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# CISDA Development Process for Decision Aids to Support Self-care Decision Making

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PHILOSOPHY

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## **ABSTRACT**

The self-care management of chronic disease patients is complicated by various everyday decisions that range from routine ill-structured problems, e.g., “What to eat?” to uncertain symptoms-related decisions, e.g., “Why do I feel tired?” Such decisions can have significant consequences on a patient’s health, treatment, care, and associated medical costs. Due to the complexity involved in understanding and analysing everyday decision making, there is a lack of empirical research to guide the development of self-care decision aids. This thesis aims to address this problem by formulating and illustrating the Critical Illness Self-care Decision Aid (CISDA) process through a coherent, structured, integrated design and development process using a case study. Following a literature review, the problems in current approaches and the criteria needed for the development were derived from evidence-based frameworks such as chronic disease management, decision aids standards and complex interventions development process for future designs. Mixed methods were used including: focus groups, interviews, questionnaire, Cognitive Work Analysis and case scenarios for not only constructing an account of self-care needs and decisions but also to evaluate the development process and the decision support provided involving patients, doctors, caregivers, non-medical experts like psychologists and IT/Systems engineers. The CISDA process consists of: (i) needs assessment, (ii) theory formation, (iii) modelling, (iv) integration, (v) interface design and development, and (vi) evaluation for addressing the relevant intersection of human factors, systems engineering, and software engineering. This thesis should prove useful to not only systems engineers but also to a range of practitioners concerned about decision making, maintaining a user's cognitive perspective during specification and analysis of a complex system.

*“At first people refuse to believe that a strange new thing can be done, then they begin to hope it can be done, then they see it can be done – when it is done and all the world wonders why it was not done centuries ago.”*

Frances Hodgson Burnett

The Secret Garden

*Dedicated to my mum, dad and many older adults who have given valuable time to assist me in this research. Together, we shall strive to help people better manage chronic illness.*

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## **Acronyms**

AH – Abstraction Hierarchy

ADH – Abstraction Decomposition Hierarchy

BHF – British Heart Foundation

CCM – Chronic Care Model

CDPM - Chronic Disease Prevention and Management

CISDA – Chronic Illness Self-care Decision Aid

CVD – Cardiovascular Disease

CWA – Cognitive Work Analysis

DA – Decision Aids

DSS – Decision Support System

IPDAS - International Patient Decision Aids Standards

MRC – Medical Research Council

NDM – Naturalistic Decision Making

OO – Object Oriented

OOD – Object Oriented Design

OOP – Object Oriented Programming

PtDA – Patient Decision Aids

SOCA - Social Organization and Cooperation Analysis

SRK – Skills-based, Rules-based and Knowledge-based

STS – Socio-technical Systems

STSD – Socio-technical Systems Design

UCD – User-centered Design

UML – Unified Modelling Language

## Chapter 1 INTRODUCTION

---

*“...[When patients] participate more actively in the process of medical care, we can create a new healthcare system with higher quality services, better outcomes, lower costs, fewer medical mistakes, and happier, healthier patients. We must make this the new gold standard of healthcare quality”*  
Charles Safran (Ferguson 2007, page iii)

The use of healthcare technologies to improve self-management of chronic illness is becoming increasingly common, but these technologies face significant challenges in their design, development and deployment (Akinçi and Patel 2014; Adsul et al 2015). The International Patient Decision Aid Standards (IPDAS) suggests that patient decision aids (PtDAs) should be systematically developed, user-tested and open to scrutiny, with a well-documented development process. In reviews of PtDAs, only a minority of the decision aids met IPDAS criteria in the design (O'Connor et al., 2007; Adsul et al 2015). A primary aim in writing this thesis is to develop a ‘well-documented development process’ that IPDAS seeks.

Campbell et al. (2000) suggests that there are difficulties in defining, developing, documenting and reproducing complex interventions in healthcare. These difficulties are mainly due to gaps in understanding fundamental and applied questions, particularly related to the decision making problems faced by patients in their everyday self-care (Hoffman et al., 2014). For instance, although some of the severe consequences of chronic illness can be minimized through vital signs monitoring tools, and devices have been developed to remind patients when to take their medication or to encourage them to comply with exercise or diet advice, self-care can become complicated by various everyday decisions. Such decisions range from routine but ill-structured problems, e.g., “What to eat?” to uncertain symptoms-related decisions, e.g., “Is this pain related to heart burn or heart attack?” to time-constrained,

treatment-related decisions, e.g., “Do I go to the doctor or wait and see?” Patients should be able to address such ambiguities through the use of appropriate decision support systems. But to date, most of the decision aids are focused on information provision for treatments like choosing between chemotherapy treatment options or, based on clearly defined rules and procedures for example “do X or Y”. While such an approach might be suitable for supporting patients in an episodic or acute (short-term, urgent) healthcare model, it is not obvious that it is most appropriate for every day, self-care decision making (Hubbard 2008; McCaffery 2007; O'Connor et al., 2004). As chronic disease is a long-term condition, rather than being provided with solutions to specific problems and expected to comply with these solutions, patients need to be proactively involved in their healthcare and decision making process (Dickson 2008).

## **Healthcare Systems**

Healthcare involves complex socio-technical systems (Whetton 2005, Baxter and Sommerville 2011) involving human (patient, healthcare professionals, caregivers, family members), social, organisational and technical factors. Thus, there is a challenge to reflect the complexity of a socio-technical system in design and development. Furthermore, such systems can fail when they move from design to deployment, either in terms of not delivering expected benefits or not integrating with existing system components or creating problems and difficulties for people who use them (Effken 2002). Due to this complexity, a multifaceted approach is required for the design of self-care decision support interventions (Foo et al., 2012, Roter et al., 1998, van Eijken et al., 2003). However, there are very few reports of design that involve such an approach. Addressing the needs of patients requires an understanding and appreciation of the challenges that they face in everyday treatment decisions, such as the side-effects of medications and interactions of drugs with patient's

diet. This could involve tailoring intervention to individual patients' health and their profile in order to support them in making everyday decisions. It is claimed that current systems have been developed based on implicit assumptions of the designers rather than understanding everyday self-care decision making or translating theory into design (Elwyn et al. 2010). Consequently, there have been few studies examining how patients' make decisions in real life (O'Connor 2003; Thorne 2003; and Haas 2006).

There is a pressing need in healthcare to study patient's decision making processes, to explore interdisciplinary approaches to designing decision aids, and to test strategies for tailoring decision support to meet patient's needs and preferences (Severinsson and Holm 2014). In addition to understanding patient decision making, there is also a need to integrate patient experiences of healthcare sociotechnical systems in the planning, designing and implementation of decision aids (El-Gayar et al., 2013; Elwyn et al. 2010). This thesis develops and illustrates the Chronic Illness Self-care Decision Aid (CISDA) development approach to achieve the above concerns through a coherent, structured, integrated design and development process. The CISDA approach is anchored on a methodical, step-by-step case study of the development of a prototype mobile application intended to help cardiovascular disease (CVD) patients in their daily decision-making. This thesis should prove useful to a range of practitioners concerned about: self-care management, decision making, maintaining a user's cognitive perspective during specification and analysis of a complex system.

## **1.1 Thesis Background**

---

This section provides background information on decision making and decision aids.

### **1.1.1 Self-care Management Decision Making**

Chronic diseases, such as heart disease, diabetes, stroke, chronic respiratory diseases and cancer, are the leading cause of mortality in the world (European Parliament Heart Group 2008). Self-care decision making for chronic disease relies on patient knowledge, experience, and receptivity to cues for maintaining health through treatment adherence and symptoms monitoring (Dickson et al 2007, Hicks & Holm 2003, Riegel et al 2000). In order to acquire this knowledge and experience, patients need to engage in active learning. Managing Cardiovascular disease (CVD) requires patients to identify symptoms and seek treatment as quickly as possible. Therefore, everyday self-care management for chronic disease is a decision making process (Riegel et al., 2009) relating to a wide range of topics, such as:

- Taking diuretics, avoiding salt, avoiding fluids, getting exercise, taking medications (Hicks and Holm 2003)
- Confusion over the effects of different foods on medication or well-being, interpretation of symptoms; lifestyle choices; adherence to healthcare professionals' recommendations (Moser & Watkins 2008; Thorne et al., 2003)
- Challenges in changing behaviour relating to losing weight or smoking cessation (Young et al., 2011)
- Managing pain and discomfort, and understanding how this relates to exercise (Ross et al., 2001)

Entwistle et al. (2004) identified decisions through observing patient's participation in routine practice. These decisions basically are "to do" or "not to do" with something like medication, diet or exercise. In general, making decisions, choosing what to do, depends on cognitive functions like: the choices available at that time, situation and events (Klein 2009). In well-ordered situations, decisions are more structured and stable, where patients can think

systematically to calculate what decisions to make. Healthcare is often a complex, unstructured and unstable domain. For instance, self-care management decision making involves a lot of uncertainty and can get complicated due to various factors including: comorbidity, depression, anxiety, sleep disturbance, impaired cognition and poor health literacy (Riegel et al., 2009). In addition to these factors, a number of self-care decisions are dependent on personal circumstances, values and preferences (Witt et al., 2012). The impact of these factors can be exacerbated by ambiguity in decision situations, e.g., “Is my tiredness related to exercise, stress, or heart disease?” According to Klein and Lippa (2008) decision makers should be able to address ambiguities in decisions like chest pain or abdominal pain and their situation awareness must then guide their planning and decision making for controlling cardiovascular disease.

Due to this complexity, self-care decision making about the best course of action can be difficult for patients and health providers as many decisions have no obvious right or wrong choice (Kryworuchko et al., 2008). This complexity and uncertainty in decision making manifests in high rates of hospital readmission due to non-adherence to diet, medication or fluids, etc., (Pearson 2002; O'Reilly 2011; Dickson et al 2007). Successful self-care management requires patients to play an active role in decisions about their healthcare to identify symptoms and seek treatment quickly to achieve better outcomes (Vicente 1999).

### **1.1.2 Support for Self-care Decision Making**

Interventions to reduce self-care risk factors take the form of education initiatives, self-management programs, patient decision aids (PtDAs) or decision support systems. Education initiatives, intended to improve patients' abilities to care for themselves, play an important role in disease management programs (Dickson et al 2007). Programs that teach self-care and decision making seem to slow disease progression and prevent repeated and expensive

hospital readmissions (Hicks & Holm 2003, Shipton 1997). One example of such intervention is the community-based program in North Karelia, Finland, that reduced the CVD burden by reducing smoking rates, blood pressure and cholesterol rates in the population through a broad mix of social and medical initiatives (Ontario Framework 2007). Through active involvement, patients take responsibility for their own health, and decisions (Vicente 1999; Deber et al., 1996; Cahill 1998) which in turn results in reducing hospitalisations and healthcare costs (Lorig et al., 1999; Anderson et al., 2005). DeWalt et al., (2006) found that self-care decision making programs which included education, compliance and paying close attention to physical activity, diet, and medication helped in reducing hospitalizations and mortality rates. Despite the effectiveness of these programs, there are low rates of participation (Bethell et al. 2001; Evans et al. 2002; Melville et al. 1999; Pell et al. 1996) due to a lack of funding and support (Bethell et al. 2009).

PtDAs or Decision Aids (DAs) can also be used to educate patients and enhance the quality of their decisions by (a) providing facts about the condition, options, outcomes, and probabilities that are relevant to the patient's health status (O'Connor et al 2007); (b) providing a feature matching process (Hutton & Klein 1999) in which certain changes in health status are highlighted and compared to past experiences; and (c) guiding patients in making decisions (Barnato et al 2007) leading to decreased levels of anxiety and distress (Lin et al 2009).

PtDAs can take the form of audiotape and printed brochure (Goel et al 2001), video and brochure (Van Roosmalen 2004; Street 1995), or interactive computer technology (O'Connor et al 2004). Technology presents a variety of options to patients based on health status for effective decision making and to better manage themselves (Evans et al., 2004; Brehaut et al.; 2008, Lin et al 2009; O'Brien et al., 2009; Montori et al., 2006; Elwyn et al., 2006; Stacey et al., 2008). When patients are involved in making decisions about day-to-

day treatment they are likely to become less anxious and achieve better outcome (Vicente 1999; Deber et al., 1996; Cahill 1998) which in turn results in reducing hospitalisations and healthcare costs (Lorig et al., 1999; Anderson et al., 2005). For example, a meta-analysis of the effectiveness of over sixty decision aids (Brehaut et al., 2008) has shown that DAs improve the quality of decision relevant to patient health status, in comparison to both standard care information documents and standard education programs. Likewise, O'Connor (2009) showed that decision aids increased people's involvement leading to informed values-based decisions on treatment options. However, these studies have not measured impact on patient satisfaction, anxiety, decision uncertainty, or general quality of life (Molenaar 2000; Power 2011). The decision aids are mostly aimed at supporting patients in their decision making on an episodic, acute healthcare model (Hubbard 2008; McCaffery 2007; O'Connor et al., 2004) and less on supporting everyday decision problems to do with diet or medication.

## **1.2 Complexity in Supporting Everyday Decision Making**

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This section highlights the complexities involved in supporting everyday decision making.

### **1.2.1 Decision Ambiguity and Uncertainty**

Researchers have found that real-world decision making exhibit the following problems:

- Ill-structured problems – Patient problems are not well-structured and for example they are not sure about the side-effects or interactions with food.
- Communication Problem: information is missing, ambiguous or overloaded.
- Consequences of decisions and accountability due to uncertainty: patients frequently face various problems of self-care like, what to eat?



- Multiple players are involved in self-care support including family, caregivers, doctors, nurses and others.

It is important for the design of any decision aid to respond to these problems.

### **1.2.2 Self-care Coupling**

PtDAs are usually designed with the idea that healthcare decisions are structured and discrete, whereas everyday self-care decision making involves, and is affected by:

- The patient's representation of the problem (involving uncertainty).
- The patient's medical history, general health, and current treatment.
- The context in which decisions are made.
- Patient's cognitive ability.
- Patient's context, work organization, and environment.

This makes it very difficult for designers to predict the actions or to trace the implications caused by any of the above factors. For e.g., 'feeling tired' could be not just the cause of over exerting or exercise but can also be due to skipping medication. Due to this coupling, studies have shown that there are high rates of hospital readmission (Pearson 2002; O'Reilly 2011; Dickson et al 2007).

### **1.2.3 Time Stress**

Managing CVD requires patients to identify symptoms and seek treatment quickly. Studies have shown that lack of dietary discretion, medication compliance, and failure to detect symptoms and act early are found to be the primary contributors to acute hospitalisation (Dickson et al 2007). Therefore, decision support system should help in the knowledge

gathering process about patient's everyday well-being and activities to make appropriate decisions.

#### **1.2.4 Heterogeneous Perspective**

Different people use different approaches in their decision making depending on their education, knowledge, and disease experience. Each user uses different learning styles including: perceptual (information extracted from the environment), cognitive (mental processing of that information), and emotional (personal feelings, preferences and attitudes that influence both the perceptual and cognitive modalities) (French et al., 2012; Fisk and Rogers 1997). Also the decision approach taken by a novice would be different than that of an experienced. For example, a novice might follow a sequential instruction based analysis approach than someone has some experience in dealing with similar problem (Zsombok and Klein 2014). Designers should build systems that are flexible enough to support both novice, experienced self-carers and different learning styles.

#### **1.2.5 Social Perspective**

Self-care decision making does not happen in a vacuum, rather it consists of many people like the patient, family, healthcare professionals and caregivers. This creates a strong need to identify various people, their roles and tasks to provide clear communication.

These challenges in self-care decision making lead to complexity in the development of effective decision support systems.

### 1.3 The Problem - Design of Decision Aids

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Although self-care might seem to be a straight-forward task of following a doctor's advice, the above complexities impose greater challenges, hence decision aids are often described as a burdensome process for healthcare providers due to the lack of implementation guidance (Wilson et al., 2010; Johnston et al., 2011). Riegel et al. (2009) states that self-care involves decision making but it is not clear what decisions patients face. For example, decision making requirements of elderly patients at home are not well represented in clinical trials (Herrera et al 2010). Literature shows that chronically ill patients have to deal with numerous problems in their day-to-day medication management (Haslbeck and Schaeffer 2009), so lack of knowledge and decreased adherence have been the major causes for emergency hospitalizations (Heinrich and Kuiper 2012). Due to this, patients are not receiving appropriate support for day-to-day self-care management. For example, in the US there are nearly 100,000 emergency department visits for adverse cardiac disease and diabetic drug events (Centres for Disease Control and Prevention 2011).

Zao et al., (2008) lists the hardships encountered by elderly patients including: memory degeneration (e.g., missing medicine doses); information shortage (e.g., age and multiple conditions could lead to lack of information on medicine and/ diet); information management (e.g., forget doctor's advice); and emergency care (e.g., lack of symptoms recognition and appropriate action). This shows that it is not possible to codify all the self-care decision making needs in a set of rules and procedures (Klein 2009). Decision making intervention needs to function as an extension of the individual's cognitive ability and support collaborative teamwork rather simply aimed at specifying compliance to clearly defined rules and procedures for example, "do x or y" (Hubbard 2008; McCaffery 2007; O'Connor et al.,

2004). Some decision aids are focused on information needs related to treatment for example, renal replacement therapy and withdrawing or withholding dialysis (Murray et al., 2009). Riegel et al. (2009) states that if patients face decision problems it is important to not just treat one symptom, they also need to understand the impact of their decision on the symptoms in relation to their health condition.

This mismatch (between decision aids assuming structured decision problems and everyday life involving unstructured problems) results in limited availability of systematic operational guidance about how best to develop complex interventions. To effectively support decision making, the design of interventions requires a systematic approach with a strong rationale for design for considering the context, environment, cognitive ability, learning styles and explicit reporting of the intervention development process (French et al., 2012; Van Bokhoven et al., 2003; Davies et al., 2010; Brownson et al., 2012, Ng et al., 2014). This raises the question of ‘How do we design patient self-care decision aids in which everyday healthcare decisions are made?’”

## **1.4 Research Question**

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This thesis details a coherent, structured, integrated design and development process applied to support CVD self-care and decision making. To achieve this, the thesis explores three research questions. These are important questions to address as they will help to develop a deeper understanding of patient experiences and decision needs and to develop a systematic process for the design of self-care decision support systems.

### *1. How can we describe everyday decision making of CVD patients?*

Although there is a lot of literature on compliance, adherence and self-care needs, there is little research on questions such as,

- How do patients actually self-manage in day-to-day life?
- What decisions do they make in day-to-day self-care?
- How do doctors support patients in decision making?

Due to this lack of research, there is a risk that PtDAs could be designed according to acute illness needs or conventional models of medical expert's practices which may not be appropriate for patients. These could either assume that the patient should play no role in decision making and only follow the advice and guidance set out by the medical experts, or that 'medical decision making' should always follow the same approach (the one used by medical experts). There are many theories that help us to understand decision making. Rather than reinventing the wheel, application of theories would help us to understand the uncertainty, context and influence of people in their decision making and thereby extract the specific attributes (in terms of software engineering) and functions required to support decision making. Therefore, understanding and describing patient's decision making is imperative for the development of effective support and for producing support based on research into what is vital for the patients and how decisions are made.

### *2. How can we translate the descriptions of CVD patient decision making (Q1) into specifications for software implementation?*

Using the attributes and functions needed for DAs, this research question explores the decision process, various courses of actions and the role of different stakeholders using modelling tools for the implementation of DAs to support based on 'how they self-manage and make everyday decisions?'

As mentioned earlier, there is little research on everyday self-care decision making, decision making process, influence of patient's knowledge and experience. It is unclear as to - What strategies are used in decision making? What are the various courses of actions patients take? What are the roles and tasks of different stakeholders? Due to a lack of this understanding most of the decision support tools are designed to reflect – ‘how *should* patients make decisions?’ rather than ‘how *do* patients make decisions?’ Therefore, the systems are focused on developing decision systems based on clearly defined rules and procedures by giving ‘Yes’ or ‘No’ to decision problems. Patients should be able to address ambiguities through the use of appropriate self-care tools. To better support patients in their day-to-day decision making it is essential to understand ‘How to model everyday decision making?’ ‘What are the various courses of actions patients take?’ ‘What are the roles and tasks of the stakeholders in the decision process?’ ‘How do patients use their skills, knowledge and rules in decision making?’ This understanding should help to model the decision making process to identify the interactions, the inputs, various courses of action and outputs for the design and evaluation of the system.

*3. Given the specification developed (in Q2), how can we design decision aids to support everyday self-care decisions?*

Self-care decisions not only affect the patients but, also affect other people involved in the care (like caregivers, family, and doctors) and are affected by the health condition and environment. Understanding the influence of these effects can be achieved by exploring the existing support for decision making to identify the gaps for formulating a design approach. There needs to be design approaches to bridge the gap between ‘patients’ and ‘systems’ and for understanding how ‘people’, their ‘environment’, ‘work organisation’ and ‘technology’ processes are interlinked. This can be achieved by exploring existing approaches for

software engineering to propose a step-by-step process for the design of self-care decision aids.

## **1.5 Major Contributions**

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The major contribution of this thesis is the design process for the development of patient decision aids. The design process is developed using an iterative, User-Centred Design (UCD) approach involving patients, doctors, caregivers, and IT professionals. This means that rather than centring the design on an individual user, i.e., the patient, there needs to be focus on the design of the Socio-technical system in which decision making is performed. As there are many chronic diseases, the design approach is applied to support CVD management to provide guidance for software designers. Through the application of the design process, this thesis helps to provide a deeper understanding of how patients self-manage and make decisions; understand the natural decision making using a conceptual model; the decision process and the design approach for developing and implementing self-care decision aids. An overview of the significant contributions is given below:

(a) Based on a review of existing software engineering approaches and frameworks for supporting chronic diseases a systematic step-by-step design process for the design of self-care decision aid is developed using a user-centred design approach (Chapter 3). Socio-technical system using Cognitive Work Analysis (Chapter 7) is used to develop specifications for software implementation, using UML and object-oriented development for prototype (Chapter 8, 9). This approach addresses some of the criticism on the lack of guidance and step-by-step analysis involved in the development and implementation of

systems. Rather than replacing or challenging the approaches outlined in ISO Standards and other guidance, the thesis focus is to provide supplementary material to illustrate the manner in which a design process proceeds from initial requirements capture to implementation.

(b) This thesis makes significant contribution to research on patients' everyday healthcare decision making including: (i) formulation of a theoretical framework for describing decision making based on the existing decision theories and how doctors support patient in self-care decision making (Chapter 6); (ii) how decision making can be extracted and synthesized into a model to capture the high-level systems view for understanding the interactions, decision inputs, course of actions and outputs using CWA (Chapter 7); and (iii) and to inform requirements for the decision aid (Chapter 7).

(c) There is a gap between CWA (socio-technical systems design) and systems implementation. This is mainly due to the fact that systems engineers have difficulty in understanding the requirements or models generated by cognitive engineers (and cognitive engineers rarely present their findings in a manner conducive to systems engineering practice). Moreover, there are no guidelines that help in extracting or converting between these cognitive engineering and software design approaches to development. This thesis not only contributes to requirements engineering for supporting self-care decision making but also to capture and convert the resulting models to systems implementation using object oriented approach. This thesis provides a novel contribution to bridging the gap between CWA and software implementation.



## 1.6 Study Objectives and Approach

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As self-care decision making happens in a complex dynamic environment there is a need for a step-by-step process for developing interventions. The main aim of this thesis is:

*To formulate a process for the design and development of self-care decision making support aids as well as to provide guidelines for analysing patient decision making and integration into design.*

This aim is achieved through an iterative user-centred design approach involving patients, doctors, IT professionals, and other stakeholders. The research objectives are to:

- Identify the design process and models using literature reviews for the design and development of chronic disease management (Chapter 2).
- Formulate a design process for the design and development of self-care decision aids (Chapter 3).
- To provide guidelines/ insights for designers for analysing, modelling, extracting requirements and DA implementation (Chapters 5 – 10).

The approach emphasizes a commitment to a full analysis for uncovering the user needs and the deep structure of the processes involved in supporting self-care decision making rather than the development of the actual product. This thesis does not involve:

- Product Development: As there is a pressing need for supporting self-care management decision making to reduce the burden of the disease, the focus is not on the end product but in synthesising a systematic design process.

- Definitive randomised controlled trial and long term implementation (Campbell et al., 2000): Obviously a more detailed controlled trial and a long term implementation with user over a period of 3-6 months would be ideal, it was not feasible as:
  - Patients currently do not use smart phones and there is no guarantee that people will have the right phones (Android).
  - If the prototype was to be used as part of the patients' care regime it could constitute as a medical device and would need to be subjected to Medical Device Agency (MDA) approvals.

Although the CISDA design process proposed in this thesis provides details of the features needed to consider in the development of self-care management Das, the study shows less focus on the:

- User context, visual, sensory, and physical capabilities.
- Environment.
- Integrating various resources available in the healthcare organization, and

For e.g., Review Study I (Chapter 2) shows the use of various sensors to capture the environment/ context of use, but in this thesis, systems approaches to integrate or map the sensors is explored but it is not really applied and tested. Similarly, the roles and tasks of various human involved in chronic disease management is explored and considered in the design but integration of health records or other healthcare resources are not considered except for linking to patients.co.uk website to provide information.

## 1.7 Thesis Overview

To achieve the thesis aims and objectives a six phased CISDA design approach is proposed. Each phase is described in respective chapters to highlight the various studies conducted including literature review, interviews and focus groups with patients, interviews with doctors, workshops with IT specialists and Psychologists. These studies are shown as inputs for the phases in Figure 1.1. The numbers inside brackets ‘()’ refers to the thesis chapters. The outcomes of the phases resulted as inputs to the next phase. Figure 1.1 provides an overview of the thesis structure to help designers in the extraction of software requirements for the implementation of the decision aids.

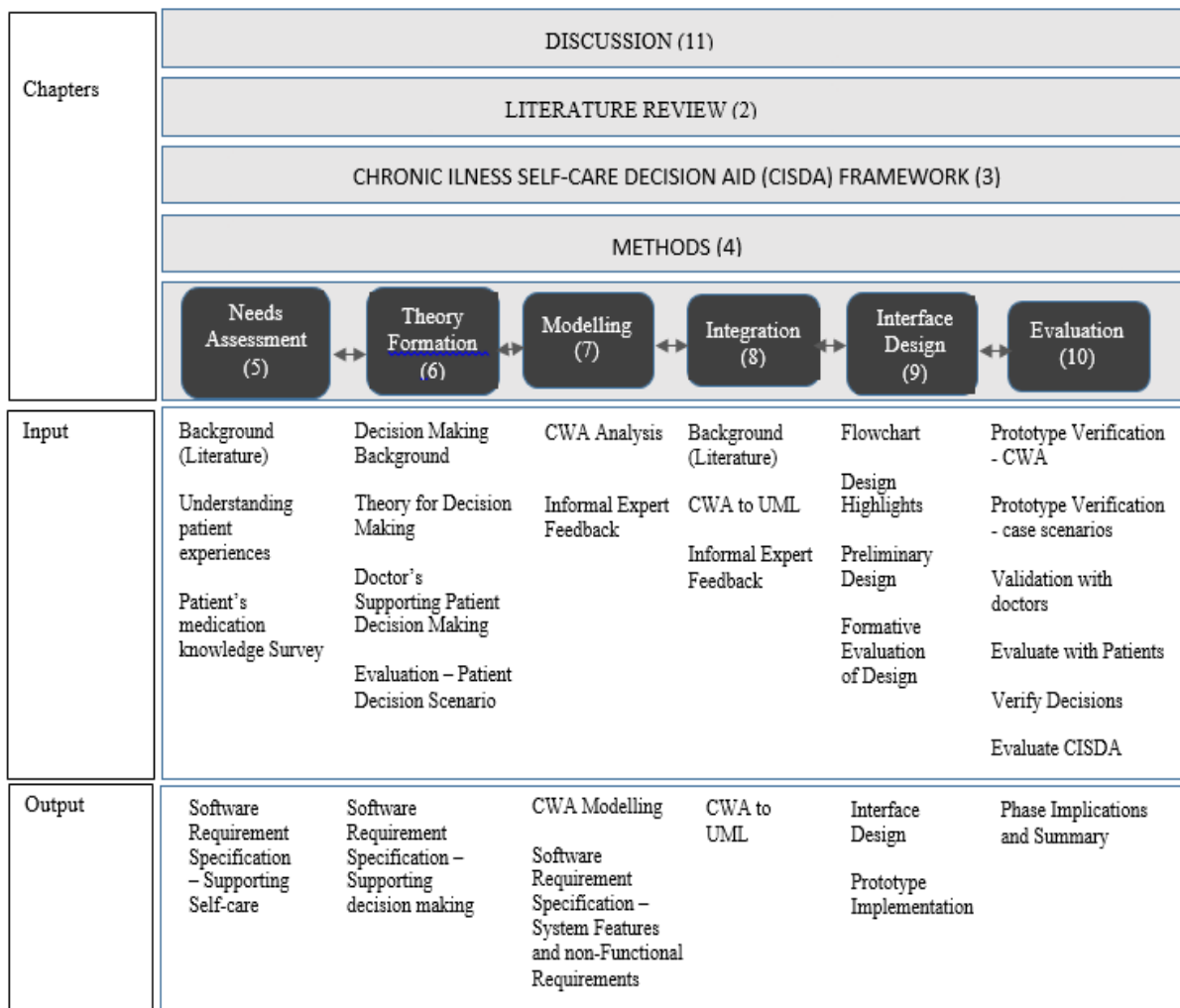


Figure 1.1 Thesis Overview

## 1.8 Terminology

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This section provides definitions for some of the terms used in this thesis.

### **Self-Management**

Although self-management has various definitions in the literature, the Department of Health (2005) definition is: *“The actions individuals and carers take for themselves, their children, their families and others to stay fit and maintain good physical and mental health; meet social and psychological needs; prevent illness or accidents; care for minor ailments and long term conditions; and maintain health and wellbeing after an acute illness or discharge from hospital.”*

Self-management is also defined as: *“The assistance caregivers give patients with chronic disease in order to encourage daily decisions that improve health related behaviours and clinical outcomes. Self-management support can be viewed in two ways: as a portfolio of techniques and tools that help patients choose healthy behaviours; and a fundamental transformation of the patient–caregiver relationship into a collaborative partnership.”* (Bodenheimer et al., 2005)

Based on the above definitions the term self-management in this thesis involves:

- maintaining health and well-being through treatment adherence (diet, medication and exercise), and
- making decisions to improve health related behaviours and clinical outcomes.

### **Self-care (Management) Decision Making**

Most theories emphasis decision making as a choice between options. For the purpose of this thesis decision making is based on Dickson et al., (2007 pg. 4) work: *“Self-care decision*

*making requires that symptoms are perceived and interpreted. A timely response to symptoms requires the ability to reason, make associations, and foresee consequences of actions.”*

### **Compliance and Noncompliance**

Compliance is defined as *“The extent to which the patient’s behaviour matches the prescriber’s recommendations.”* (Haynes, Taylor and Sackett, 1979).

### **Adherence**

Adherence is defined as *“The extent to which the patient’s behaviour matches agreed recommendations from the prescriber.”* (Barofsky, 1978).

### **Socio-technical Systems Design (STSD)**

STSD is an approach to design that considers human, social, organisational and technical factors in the design. The importance of STS in this thesis is more on the ‘system’, ‘environment’ and ‘work organisation’ (Mumford 1985).

### **User-centred Design (UCD)**

UCD is a combination of the ‘people’, ‘work’, ‘environment’ and ‘technology’ (Preece et al., 1994) According to Norman (1986) the goal of a user-centred interface, is to provide an intelligent, understandable, tool to bridge the gap between people and systems.

### **Software Design and Development**

Software design and development refers to the project processes (e.g., planning, assessment, risk management) and technical processes (e.g., requirements analysis, design, implementation, integration, validation) that is usually carried out by software engineers.

## **Systems Engineering**

Systems engineering is defined as "an interdisciplinary approach and means to enable the realization of successful systems. It focuses on defining customer needs and required functionality early in the development cycle, documenting requirements, then proceeding with design synthesis and system validation while considering the complete problem" (INCOSE - the International Council on Systems Engineering).

### **The Term ‘Patient’ or ‘User’**

The term ‘Patient’ is used to refer to people diagnosed with CVD. The term ‘User’ is used to refer to the system users.

## **1.9 Thesis Structure**

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The structure of this thesis is described here.

Chapter 2: This chapter lays the groundwork for this thesis through literature review for: (i) identifying the criteria needed for review based on an evidence-based approaches; (ii) gathering information on existing models and frameworks for chronic disease management, decision aids and complex medical intervention development; (iii) exploring the type of decision support, design process, software approaches, its implications, and the development phases by reviewing the literature; and (iv) highlights the problems in the current approach along with the gaps.

Chapter 3: Based on the literature review on Chapter 2, this chapter addresses the thesis aims and research question 3: “How to design decision aids to support everyday self-care decisions?” by proposing the CISDA process for the development of DAs.

Chapter 4: The purpose of this chapter is to provide a brief overview of the research methods used in the CISDA process for gathering user needs, analysis, integration and evaluation.

Chapter 5: This chapter tries to explore elderly CVD patients’ experience, knowledge, and decision needs in day-to-day self-care decision making using focus groups and questionnaires for extraction software requirements.

Chapter 6: This chapter along with Chapter 5 addresses the research question 1: “How to describe everyday decision making for software design and development?” by proposing a descriptive approach to understand patient’s decision making based on decision theory and how doctors support in decision making. This phase helps in extracting software requirements for supporting decision making.

Chapter 7: Based on Chapter 6 understanding on decision making this chapter addresses research question 2: “Can everyday self-care decision making be extracted and modelled for software implementation?” This question is addressed in two parts, first modelling (Chapter 7) and implementation (Chapter 8). The software requirements specification from Chapters 5 and 6 are used in the CWA analysis.

Chapter 8: This chapter helps to fill the gap between CWA analysis and software design and development by capturing and converting the resulting CWA models to UML.

Chapter 9: This chapter provides an overview for the design of mobile interface based on UML design.

Chapter 10: The CISDA process and decision support is verified, validated and evaluated using use case and user-centered evaluation techniques involving patients, doctors, psychologists and IT professionals.

Chapter 11: Provides summary of the CISDA process, its applicability, usefulness and the caveats.

Chapter 12: Provides a summary of thesis findings, main contributions, limitations and future contributions.

## **1.10 Thesis Publication and Presentation**

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### **1.10.1 Publication**

1. Anandhi V Dhukaram and Chris Baber. A Systematic Approach for Developing Decision Aids: From Cognitive Work Analysis to Prototype Design and Development, Journal of Systems Engineering (Accepted for publication) (Chapter 8).
2. Dhukaram, A. V., & Baber, C. (2015). Modelling elderly cardiac patients decision making using Cognitive Work Analysis: Identifying requirements for patient decision aids. International journal of medical informatics, 84(6), 430-443 (Chapter 7).
3. Anandhi V Dhukaram, Chris Baber, Paolo De Stefanis, (2012) "Patient-centred cardiovascular disease management – end-user perceptions", Journal of Assistive Technologies, Vol. 6 Iss: 2, pp.105 – 122 (Chapter 5, 10).



### **1.10.2 Speaker & Presentations**

1. Anandhi V Dhukaram (2015) Supporting Everyday Cardiovascular Disease Self-care Decision Making: Are we there yet? Telemedicine & eHealth August 17-19, 2015 Houston, Texas, USA (Chapter 2, 3)
2. Anandhi V Dhukaram (2015) Application of Persuasive Techniques in the design of mobile eHealth Systems. Telemedicine & eHealth August 17-19, 2015 Houston, Texas, USA (Poster). (Chapter 2, 3)
3. Anandhi V Dhukaram (2015) Cognitive Engineering approach for creating sustainable solutions to complex industrial design challenges. Fifth International Conference on Industrial Engineering and Operations Management, Dubai March 3-5, 2015 (Chapter 3, 6,7)
4. Anandhi V Dhukaram (2014) Socio-technical Systems thinking for higher education provision. Oxford Higher Education Symposium, Oxford, UK August 2014 (Chapter 3).
5. Anandhi V Dhukaram and Chris Baber(2013) Elderly Cardiac Patients Medication Management - Patient Day-To-Day Needs and Review of Medication Management Systems, IEEE ICHI 2013 Conference at Philadelphia, USA, September 2013 (Chapter 5, 6)
6. Anandhi V Dhukaram (2013) An Integrated Design Approach for Supporting Elderly Cardiac Patient Self-Management. Doctoral Consortium Poster, IEEE ICHI 2013 Conference at Philadelphia, USA, September 2013 (Chapter 5, 7)
7. Anandhi V Dhukaram et al (2012) Patient-centred Cardio Vascular Disease Management: End-user Perceptions, Journal of Assistive Technologies, Vol. 6: 2, pp.105 – 122 (Chapter 5)

8. Anandhi V Dhukaram (2012). Application of Cognitive Work Analysis Approach to Complex Socio-technical Systems: Cardiac Patients Decision Support System. IEEE MDM 2012 – The 13<sup>th</sup> International Conference on Mobile Data Management, Bangalore, India, July 23, 2012 – July 26, 2012. (Chapter 6,7, 8)
9. Anandhi V Dhukaram et al. End-User Perception Towards Pervasive Cardiac Healthcare Services: Benefits, Acceptance, Adoption, Risks, Security, Privacy and Trust. Pervasive Health, Dublin, May 2011. (Chapter 5)
10. Anandhi V Dhukaram and Chris Baber. An approach to designing interactive decision support system for cardiac patients. HCI 2011 conference, Newcastle Upon Tyne. (Chapter 5,7)

### **1.11 Research Visits**

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1. University of Twente (2011). Design for Self-care decision making. Application for Web and Mobile (1 week) (Chapter 9)
2. Anandhi V Dhukaram (2012). Requirements Extraction for Self-care decision aids Using Cognitive Work Analysis. Microsoft Research Lab, India (Chapter 6, 7)
3. Anandhi V Dhukaram (2012). Requirements Extraction for Self-care Decision Aids Using Cognitive Work Analysis. HP Research Lab, India (Chapter 6, 7)
4. Anandhi V Dhukaram (2012). Requirements Extraction for Self-care decision Aids Using Cognitive Work Analysis. IBM Research Lab, India (Chapter 6, 7)
5. Anandhi V Dhukaram (2012). Application of Cognitive Work Analysis. IIT, India (Chapter 3)

6. Anandhi V Dhukaram (2013). Framework for Designing Self-care Decision Aids Using Cognitive Work Analysis and UML. Qualcomm Research Lab, India. (Chapter 3, 6, 7, 8)

## Chapter 2 LITERATURE REVIEW

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*Creative Thinking “is looking at the same thing as everyone else and thinking something different”.  
Albert Szent-Gyorgyi 1893-1996, Noble prize winner, Physician.*

This chapter lays the groundwork through: (i) literature review to explore decision aids in general; (ii) review of the models and frameworks for chronic disease management, decision support, and complex medical interventions; (iii) literature review to understand the design process and development phases used; (iv) overview of software approaches to the design of systems; (v) problems with the current approaches and its implications. This study shows lack of structured approach in the design of decision aids.

### 2.1 Introduction

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As mentioned in Chapter 1 there is increasing evidence that chronic diseases can be controlled and managed through effective self-care management and decision making initiatives to reduce unplanned hospital admission, improve healthcare outcome, enhance patient experience and achieve substantial cost reductions (Griffiths et al 2007, Jaarsma et al 1999). There are criticisms that the current systems seem to have been developed based on implicit assumptions of the designers rather than translating theory into design (Elwyn et al. 2010). Self-care decision aids have tended to collect and display vital signs or act as information provision sources, which might be due to the domination of biomedical care models for acute hospital-based illness care (Anderson 1995). Many decision aids seem to be designed on the basis of paternalistic approaches to healthcare where patients are expected to follow instructions rather than make their own decisions (Thorne 2003).

In order to support decision makers, it is essential to understand the current support and guidance available, their gaps and implications. This chapter explores the design process, theories and models used in the development of current decision aids to provide groundwork for this thesis. The reviews are used to identify the gaps in the current support to contribute to research questions 1, 2 and 3 (section 1.4). This chapter helps in re-thinking the current approaches from the one that is designed for short term, episodic, acute illness to an ongoing, pro-active and planned management of chronic diseases.

## **2.2 Decision Support Systems – Review**

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This section explores the design of decision aids through literature review of patient decision support systems as shown in Figure 2.1. It should be noted that the literature uses a variety of names including self-management systems, self-care systems, patient decision aids (PtDA), decision support systems.

## **2.3 Method**

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### **2.3.1 Literature Search Strategy**

Electronic literature searches were performed using Taylor and Francis Online, SAGE Journals, Biomed Central, DOAJ, Science Direct, Wiley Online Library, Medline and PMC databases. The key words and criteria used for literature searches are in Figure 2.1.

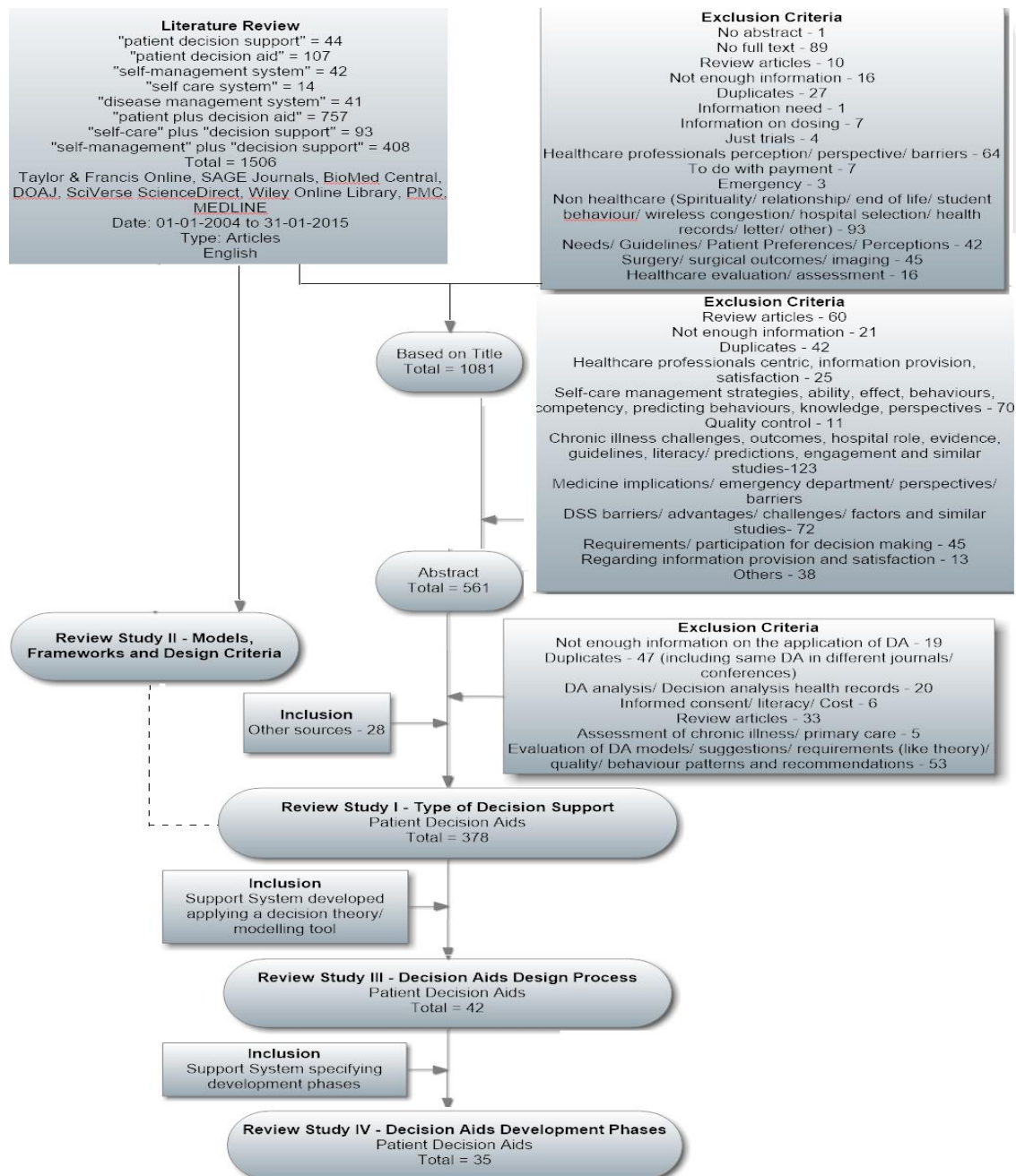


Figure 2.1: Literature Review Selection Process

### 2.3.2 Assessment for Inclusion of Studies

Study inclusion and exclusion criteria were derived prior to the review as summarised in Figure 2.1. The retrieved articles were rejected based on the title or abstract if they failed to meet the review inclusion criteria. The full text of the article was obtained when an abstract could not be rejected with certainty for further reviews.

## 2.4 Results

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A total of 1506 articles were extracted using the literature search strategy. Based on each of the literature paper titles and the exclusion criteria, the search was refined to 1081 papers. On further review 561 papers were shortlisted after the exclusion criteria. The papers were further shortlisted and the reviews are discussed in the following sections.

### 2.4.1 Review Study 1 – Type of Decision Support

This section explores the type of decision support detailed in the reviewed papers with the various implementation approaches used as shown in Table 2.1. A total of 378 patient decision aids were considered in this study. DAs were paper-based, community based collaborative learning, online, computer-based, audiotape, video, game-based, shared decision making (face-to-face), mobile (smartphone-based), telehealth (wireless), diary, animated, web, email messages, entertainment education and tablet-based. Table 2.1 shows the decision support provided. For instance, support for surgery, medication, cancer was grouped into “Treatment” (about 32%), PtDAs that provided support for medication intake and rehabilitation were grouped under “Self-care” (about 54%); PtDAs that dealt with screening decisions were grouped into “Screening” (11%). The rest of the decision aids were listed separately (3%). Treatment decisions were aimed at guiding patients for a specific treatment by providing options and benefits, evidence probability, risks and education. For e.g., Knee replacement for arthritis – “to do” or “not to do”, “what are the consequences”. These are generally based on probability or rules or algorithm. Self-care support decision aids help in treatment adherence (e.g. timely medication intake) and skill building through education and shared decision making.

Table 2.1 Types of Decision Support and Summary of Implementation Used

Decision Support	Frequency	Delivery	Type of decisions	Design Approach	Implementation Based on
Treatment	121	Paper-based, Computer-based, interactive CD-ROM, game-based, audio, community-based, shared-decision making	Treatment options, pros and cons, shared decision making, values clarification, research-evidence based suggestions, risks, symptoms, education	Iterative, patient-centered, multi-disciplinary team, Ottawa, IPDAS, UK MRC, software-based, Delphi process, family-centered, usability design, Agile	Bayesian network, Markov model, Guidelines based, decision rules, theory-based, structural equation modelling, normative judgements, Probability-based, decision tree, Self-efficacy, Expected Utilities, Prospect theories, Theory of reasoned action, theory of planned behavior, Probability-based, Rule-based system, Multi-criteria, Heuristics Evaluation, Utility theory, Algorithm-based, Judgement heuristics and cognitive biases Behavioural theory and models, Case-based reasoning, Learning theory and entertainment, Expected utility model, Behavior change theories, Activity theory, Information Processing Theory, Theories from psychology, and self-efficacy.
Self-care	203	Face-to-face, phone (voice), Mobile, Monitoring, computer-based, Telehealth, web-based, Educator and Patient online collaboration, tablet-based, online diary, animated web, e-mail, Entertainment education	Treatment adherence and self-care adherence, medication management, coaching, self-monitoring, shared decision making, Symptoms, warning signs, monitoring	Distributed system, CCM, Usability-centered, Human Factors, systems-based, User-centered, UK MRC, patient-centered, Socio-technical, Iterative, Ottawa, IPDAS, Ontario, Human-Computer Interaction	Algorithms-based, Multi-criteria, Naturalistic Decision Making, Heuristics, behavioural model, Tree analysis, cognitive-psychological-behavioral, theory-based, Activity theory, Behavior change theories, Utility theory, Algorithm-based, Self-efficacy
Screening	43	Collaborative learning, print, web-based, computer-based, multi-media, e-mail	Information on screening, provides options, Guidelines, Case-based scenarios, Data driven, Rank-order - "Yes" or "No"	Iterative, collaborative, Stakeholders, CCM, Ottawa framework, IPDAS	Multi-criteria analysis, rule-based, theory-based, structural equation model, behavioural factors, Markov model
Pre-donation of autologous blood	1	Booklet and audiotape	Probability-based	Ottawa framework	Rule-based
Clinical Decision	1	Computer-based,	Communication model for preferences	Framework	Rule-based
Risk Management	2	Paper-based, community-based	Options Evaluation	Collaborative care	Theoretically guided, Rule-based
Genetic testing	2	Paper-based	Options Evaluation		Rule-based
Self-tests	1	Online	Information on testing	Iterative, IPDAS	Theoretically guided
Advanced life, Surrogates	1	video	Based on knowledge questionnaire		Rule-based
Disclosure	1	Online	Evaluation	IPDAS	
	2	Computer-based,	Information provision	Ottawa Decision Support	



Table 2.2 Models for Chronic Disease Management and Decision Aids

Framework/ Models	No. of Studies	Quality Criteria for Decision Aids
IPDAS (Connor et al., 2009)	263	<p>IPDAS (<a href="http://ipdas.ohri.ca/">http://ipdas.ohri.ca/</a>) Collaboration specifies a set of criteria required for the design of effective decision support interventions. IPDAS is a collaboration formed of researchers, practitioners and stakeholders from around the world. The 12 domains of the IPDAS Quality Criteria Checklist are:</p> <ol style="list-style-type: none"> <li>Using a systematic development process – focuses on patient's needs assessment, develop and review of decision aids with patients.</li> <li>Providing information about options – identify patient's needs to understand their health condition, and all medically reasonable options they have to address the condition, including each option's potential benefits, harms and side effects.</li> <li>Presenting probabilities – display of information on patient decision aids to help patients understand the possible benefits and harms of their choice, and the chances that these will occur in the form of numbers, visual aids, tailoring and framing decision making.</li> <li>Clarifying and expressing values – focuses on understanding and modelling decision making process through detailed concepts, scenarios, and methods for options comparisons.</li> <li>Using personal stories – understand patient's decision making needs, use of case scenarios, narratives and patient testimonials.</li> <li>Guiding/Coaching in deliberation and communication – Theories used in decision making, methods for understanding decision process (recognizing decision needs, negotiate decisions, planning and recording).</li> <li>Disclosing conflicts of interest – display unbiased information about the pros and cons of management options.</li> <li>Delivering decision aids on the Internet – because of increased accessibility for patients and the decreased costs for producing and distributing the aids.</li> <li>Balancing the presentation of options – balanced presentation of the information.</li> <li>Using plain language – Readability, well-structured and focused information.</li> <li>Basing information on up-to-date scientific evidence and tailor information to individual characteristics.</li> </ol>
CCM (Coleman et al., 2009)	176	<p>Chronic Care Model (CCM; Wagner 1998) developed in the US, is extensively used in the U.S, the U.K, Australia, New Zealand and parts of Europe. An extended version of the care model is the British Columbia's Expanded Chronic Care Model (ECCM) (Barr et al., 2003). CCM is evidence-based consisting of 6 structural dimensions:</p> <ol style="list-style-type: none"> <li>Self-management support – empower and prepare patients to manage their health and well-being.</li> <li>Decision support system – guidelines embedded into daily practice through alerts or flow sheets.</li> <li>Delivery system design – meeting patient needs, follow-up and involving non-clinicians in care.</li> <li>Clinical information systems – Gather patient data for proactive care planning.</li> <li>Health care organization – link patient and organization leaders to visibly support continuous improvement.</li> </ol> <p>Community Resources – help patient access the available resources</p>
Ottawa ( <a href="https://decisionaid.ohri.ca/odsf.html">https://decisionaid.ohri.ca/odsf.html</a> )	112	<p>The Ottawa Decision Support Framework (<a href="https://decisionaid.ohri.ca/odsf.html">https://decisionaid.ohri.ca/odsf.html</a>) is an evidence-based approach that uses a three-step process:</p> <ol style="list-style-type: none"> <li>Decisional Needs – understand patient's knowledge and expectations, values, decision type, timing, stage, learning, personal and clinical characteristics.</li> <li>Decision Support – clarify decision needs, provide facts, probabilities, clarify values, guide in deliberation and communication and monitor or facilitate the process.</li> <li>Decision Quality – Evaluate the decision making process and outcomes.</li> </ol>
MRC (Campbell 2000)	43	<p>MRC (Campbell 2000; Appendix A) framework is proposed for the design and evaluation of complex interventions informed from theory. MRC consists of sequential phases for developing randomized controlled trials of complex interventions:</p> <ol style="list-style-type: none"> <li>Theory – this phase involves exploring relevant theory to ensure best choice of intervention, hypothesis and to predict major confounders and strategic design issues.</li> <li>Modelling – this phase helps to identify the components needed for the intervention and the underlying mechanisms that will influence the outcomes to provide evidence to predict how they relate to and interact with each other.</li> <li>Exploratory trial – helps to describe the constant and variable components of a replicable intervention and a feasible protocol for comparing the interventions.</li> <li>Definitive randomized controlled trial – compare a fully defined intervention with an appropriate alternative using a protocol.</li> <li>Long term implementation – this phase is to determine if others can reliably replicate the intervention and results in a controlled setting over the long term.</li> </ol>
Ontario's CDPM ( <a href="http://www.health.gov.on.ca/en/pro/programs/cdpm/pdf/framework_full.pdf">http://www.health.gov.on.ca/en/pro/programs/cdpm/pdf/framework_full.pdf</a> )	21	<p>The Ontario Chronic Disease Prevention and Management (CDPM) Framework is evidence-based, population-based, and client-centered. It supports health care system changes from one that is designed for episodic, acute illness to one that will support the prevention and management of chronic disease through the following dimensions:</p> <ol style="list-style-type: none"> <li>Health care organisations – specifies the need to involve all health care organisations as well as those involved in care to play an active role in chronic disease prevention and management.</li> <li>Personal skills and self-management supports – involve clients, engage in shared decision making, following recommended treatment protocols, knowing when to recognize symptoms and signs, provide self-management support services and follow-up care.</li> <li>Delivery System Design – define the roles and responsibilities of care teams to meet patient needs</li> <li>Provider Decision Support – provider education, alerts, prompts, routine reporting, feedback and evidence-based guidelines.</li> <li>Information Systems – gather patient data, implement reminder and follow-up prompts, and facilitate self-management support behaviours.</li> <li>Healthy Public Policy – development and implementation of policies aimed at improving individual and population health.</li> <li>Supportive Environment – patient's context influence in physical, social and community environments to make healthy choices.</li> </ol>

Review shows that telehealth systems are also used to monitor patient vital signs to alert doctors in case of abnormality. DAs seem to have been developed based on the frameworks such as the International Patient Decision Aids Standards (IPDAS), UK Medical Research Council (MRC), Ottawa Decision Support Framework, Chronic Care Model (CCM), Ontario's Chronic Disease Prevention and Management (CDPM). In general, the decision aids seem to provide general information to specific questions for all the patients.

#### **2.4.2 Review Study II –Models, Frameworks and Design Criteria**

This section explores the models and frameworks (IPDAS, CCM, Ottawa, CDPM and MRC) to derive quality criteria features needed for the design and development of DAs. Based on Review Study I the frequency of the models in the literature along with their features are shown in Table 2.2. A rough frequency of the model is found using the key words specified in Figure 2.1 along with the model names to see how many studies have used the models or frameworks. For e.g., “IPDAS” + “patient decision support” retrieved 263 papers (excluding duplicates and ‘full text articles only’). Design, development and implementation of complex interventions can be a costly and a lengthy process in healthcare, therefore these models help in providing guidance for implementation.

Although these frameworks are widely used in the design, they provide a high-level view of what is required for chronic diseases management and development, but does not provide guidance for the development of PtDAs or ‘how to design and develop self-care decision making systems’. MRC is widely used as a general approach for designing interventions but lacks the aspects required for creating a quality decision aid as suggested in IPDAS. Moreover, MRC does not provide detailed guidance about how to design (French et al., 2012) or which software engineering approaches to use for transferring theory into design or how

to model the system. For instance, Sutton (2014) presents 14 case studies on the application of MRC. Some studies refer to the collection of evidence for understanding user needs and some studies specify the application of theories but none of the studies states the technique used in the modelling phase or the analysis of the requirements.

*Table 2.3 Design and Development Approach Applied to Decision Aids*

Criteria	Overview	Reference Table 2.2
Delivering DAs	The format used in delivering the decision aid. For e.g., internet, mobile, paper-based.	IPDAS (H)
Development Process	Specifies the development approach used for systematically developing the decision aid.	IPDAS (A) CDPM (C)
Self-management support	Provide support to empower and prepare patients in everyday self-management.	CCM (A) Ottawa (A) CDPM (B)
Needs Assessment	Development included needs assessment to determine what patients/ stakeholders needs, understand their health condition and options they have to address the condition.	IPDAS (A, B, E) Ottawa (A) CDPM (B) CCM (C)
Theory	States the relevant decision theory used for describing patient decision making.	IPDAS (F) MRC (A)
Application of theory	Use theory to systematically develop the intervention or developed a conceptual model for understanding decisions.	MRC (A)
Personal Stories	Describes the natural decision making process through personal stories, narratives or patient case scenarios.	IPDAS (E)
Decision Process Modelling	Describes the method used for understanding the natural course of action in decision making process.	IPDAS (D) MRC(B)
Presenting Probabilities/ (Step-by-step decision process)	Does the PtDAs provide a step-by step way guidelines? Display of information to help patients understand the possible benefits and harms of their choice. Algorithms or decision-trees that plot the sequence of decision making, and next steps for each point in disease management	IPDAS (C, G) CDPM (D) CCM (B) Ottawa (B)
Information Systems Interface/ Presentation	Specifies the methods used for the design of user interface to gather patient data and display of information.	IPDAS (I,J) Ottawa (B) CDPM (E) CCM (D)
Integrate	Integrate services across the health system. Understand the roles, responsibilities of various stakeholders in the health care system. Integration of information systems and community resources to help patient access the resources.	IPDAS (K), CDPM(C) CCM (F)
Environment/ Context	The incorporation of context or environments, physical and social into the framework. Take account of physiological variables, context, and identify the elements relevant to decision-making, such as benefits, harms and costs.	CDPM (G) Ottawa (A)

Many studies in the literature have concentrated on the effectiveness of the decision aids and very few have looked into how the current patient decisions aids are developed or what

engineering methods have been applied. To understand this, Table 2.3 is created based on the IPDAS, MRC, CCM, Ontario and Ottawa framework criteria that were found to be useful for understanding the design and development approach taken in the existing patient decision aids. The criteria from all the frameworks were considered as there were some differences in the approaches specified in each of the framework. For instance, IPDAS stresses the requirement for decision support systems and CCM or Ottawa on a community based approach. Table 2.3 provides the criteria with an overview of the criteria and the reference to where the criteria has been derived as supported in the literature (Flynn et al., 2013; Joseph-Williams et al., 2014; Gorini, et al., 2011; Lhussier et al., 2013; Lee et al., 2013; Stacey et al., 2014). This section shows the criteria that needs to be considered in the development of decision support systems.

#### **2.4.3 Review Study III – Decision Support Design Process**

There is a criticism that the current systems seem to have been developed based on implicit assumptions of the designers. This review is used to explore the application of theories and/or models in the design of decision aids using the criteria from Table 2.3. Forty-two reports of decision aid (DA) development using theories and/ models were selected (Appendix P).

The review found that some of the self-care decision aids address unintentional non-adherence by providing information and effective communication rather than addressing barriers for compliance such as follow-up and management of their health (Sarela 2009). The review shows that DAs might not support patients in their self-care management decision making as they concentrate on provision of information. Of course, information provision is essential to create informed patients. However, access to more information is not the same as having support for making decisions nor choosing between options.

Table 2.4 Summary of Decision Aids Design Process Review

Criteria	Review Summary
Delivery Decision Aids	Most of the decision support systems are delivered using Web or Mobile smartphones.
Development	11/42 studies have specifically mentioned the design approaches taken – Iterative/ User-centered/ Patient-centered. Other studies just provide us with systems level analysis and integration and does not specify the application of design approaches.
Self-management support	10/ 42 Decision Aids were designed for self-care. 27/42 Decision Aids were for treatment decision making. 5/ 42 Dealt with self-care and treatment decision making.
Needs Assessment	28/42 studies have gathered needs through either focus groups, interviews, literature review, and/ ethnography studies involving the patients/ healthcare professionals and other stakeholders.
Theory	20/42 studies have specified the theory used in their design process. Four studies have mentioned about the usage of theory but have not clearly specified which theory has been applied. Three studies have used MRC framework (Campbell 2000), but only one study has specified using Expected Utilities, Prospect theories.
Application of theory	Four studies have mentioned how the theory has been applied to design but only one study has applied theory to develop a conceptual (Dickson et al., 2014). The other studies have not provided details of how theory has been applied to support decision making.
Personal Stories	Although 28 studies have mentioned about needs assessment, none of the studies have described about the real-life decision making process. One study has mentioned about natural process/ personal stories but no information is provided on this.
Decision Process Modelling	Mentions Cognitive Task Analysis, user task analysis, Behaviour Change techniques and models, process models, but how these models have been applied to decision process remains unclear. Three studies have applied UML models (Chapter 3) like use cases, user scenarios and stories. Rule-based approaches have specified the use algorithms to model the decision process. Few studies have provided the systems level view of the decision aid, the components and sub-components needed. Three studies have applied MRC framework but none of the studies have specified how the modelling was done or what techniques were used for modelling.
Presenting Probabilities	One of the study provides information on the four different types of decisions used in healthcare: Informed decision making model, paternalistic model, shared decision making model, physician as an agent model. None of the other studies provide information on the decision process.
Information Systems Interface/ Presentation	Some of the studies have mentioned about the content, presentation, layout for the design of the interface. Few studies have used an iterative approach.
Integrate Environment/ Context	Integration is specified to integrate various systems, people, resources and task processes. Kwon et al., (2005) study specifies the need for developing context-aware systems. 10/42 studies have shown the need for considering the context or environment in which decision takes place but little is known how context is integrated into the support system.
Health care organisation	Although the studies show the need for involving various stakeholders to provide a collaborative approach, there is lack of evidence on the role of different stakeholders in the decision process.
Evaluation	Except three studies, all the studies have carried out some evaluation and verification in the form of pre-post test, acceptability and usability. Few studies have looked into the long-term effect of the aid.
Support type	The decision support is mainly rule-based providing “yes” or “no” answers for suggesting “do this” or “do that”. In case of information provision the decision aids provide general information to help patients make their decisions in a collaborative way. For instance, the aids focus on specific activities, concentrating on adherence which may involve asking people to record their activity or provide follow-up prompts to do the activity as in Walters et al., (2010), Pfaffli et al., (2012), and Zao et al (2008). So, there is ‘decision making’ here in terms of option selection (do x, not y) but not so much to identify option recognition and the situations when the options arise.

#### **2.4.4 Review Study IV – Decision Support Development Phase**

This study is used to gain insight into the development phase. A total of 35 patient decision aids were shortlisted based on the criteria (Figure 2.1) as shown in Table 2.5. The ‘x’ in Table 2.5 shows that the papers provide some information on the interface but not much details. Table 2.4 analysis shows that 14/35 papers state the theories for development and only three papers have specified it in the development phases but little information exists. 12/35 studies have applied some modelling techniques to model decision making and only two papers have specified it in the development phases, but do not show how the decision making is modelled. Most of the studies use a systematic approach for development involving the following phases in different order (Akl et al., 2007; Smith et al 2009; Guo et al., 2015; Sunyaev and Chomyi 2012; Ahmed 2011; Aki et al., 2007; Zao et al., 2008; Ubbink et al., 2008; Carroll et al., 2013; Anchala et al., 2013): Requirements/ needs analyses (using stakeholder/ patients/ literature); Development (may include infrastructure design and/ database design and/ prototype); Interface design (optional in few) and testing (may or may not include testing/ review). In addition to this:

Some studies (Shegog et al., 2013; Hommersom et al., 2013; Ng et al., 2014; Schmid et al 2010; Pfaeffi et al., 2012; Roberto et al., 2007) specify theory formation in the development phase consisting of requirements/ needs analyses, theory formation, development, review. Villalba et al., (2008) approach involves conceptualisation of the system involving user modelling. Sunyaav and Chorny (2012) insist on the need for understanding systems requirements.



Table 2.5 Patient Decision Aids Development Phases

Paper	Development	Theory	Modelling	Interface	Development phase	
Catherine et al., (2014)	User-centered design	Self-efficacy	Cognitive Task Analysis		Website development using theory and reviews, Feasibility Testing (FG), Usability Testing, Refinement	
French et al., (2012)	Patient-centered, Theory driven	Yes - Does not specify	Mentions behaviour change techniques		Identify problem, theoretical framework, identify techniques and models, forming solution	
Ng et al., (2014)	Patients and clinicians, Iterative	Expected Utilities, Prospect theories		x	Expert panel, Assess users' needs, Review the literature, Identify the theoretical framework, Collate the treatment options, Drafting (Alpha testing I), Review by the expert panel (Alpha testing II), Develop, Assess the readability, Review by patients and clinicians (Beta testing), Finalise the PDA	
Akl et al., (2007)	Ottawa Decision Support Framework	Ottawa Personal Decision Guide		x	Structural development, Information compilation, Platform design, Experts' feedback, Patients' feedback	
Smith et al., (2009)			Probability, Patient stories		Risk presentation study, decision aid development, identification of information needs and design preference, redesign of decision aid, acceptability and evaluation	
Anderson et al., (2013)	Usability engineering				Determine implementation barriers/ facilitators, determine usability barriers, Functional web-based prototype, Feedback	
Gupta et al., (2012)	Systems based			Human Factors design	(1) establishing AAP content and format options, (2) building a Web-based application capable of representing each content and format permutation, (3) testing this tool among stakeholders, and (4) revising this tool based on stakeholder feedback.	
Tsiachristas et al., (2013)	Systems based - patient, professional, organisation	Multi-criteria			Development phase, implementation phase	
Fonda et al., (2010)	User-centered design, system-based		System workflow	x	Requirements, design objectives, feedback, prototype	
Ko et al., (2014)				x	Appraise existing intervention, review relevant literature, assess regional context and engage stakeholders, solicit input from target population, integrate findings and refine	
Lin et al., (2014)	System-based		Schema	MVC architecture	Infrastructure design; Database design; Interface development, Implementation and presentation	
Jarupathirun (2007)	System-based		Flowchart		The design framework of DDSS, Intelligent agents, Dialectic knowledge-base module, DSS module, Visual aids module	
Dowding et al., (2004)	Iterative design methodology	Utility theory, Algorithm-based	Decision trees		1)Construction of the decision trees 2) Development of the program and content, II) Characteristics of the decision aid - 1) individualisation to the user 2) Users ability decide how much or how little information they access 3) Assessment of the individual's own values for particular treatment outcomes 4)Provision of a detailed record of information individualised to the user III) Evaluation	
Woo et al., (2014)	System-based		Rule-based	x	Presentation layer, Service layer, business layer, data layer	
Guo et al., (2015)	System-based		user stories, Use case, user task		(1) analyzing requirements, (2) designing a service framework, and (3) developing the Mobile Self-Care Support application.	

## 2.5 Software and Systems – Overview

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Review Study I and IV states some of the popular software development approaches used like user-centred design (UCD) and human computer interaction (HCI). The number of studies using the following approaches based on Review Study I:

- UCD – 108 studies
- HCI – 47 studies
- Agile – 8 Studies
- Iterative – 72
- STS and Ecological Approach– 3 Studies

Above shows the number of studies based on the explicit reference to the above methods (e.g., UCD, HCI, Agile) as stated in the papers. Review Study IV shows that decision aid designers have also applied some traditional methods for the development of decision aids.

### 2.5.1 Traditional Software Models

Traditional software processes like the waterfall model, incremental process model, evolutionary process models (prototyping, spiral model), and the unified process models are all prescriptive process models which were originally proposed to bring order to software development through a set of frameworks for developing high quality software (Pressman 2005).

#### 2.5.1.1 *Waterfall Model*

The waterfall model (Royce 1970) is a sequential design approach involving planning, analysis, design, implementation, and testing. As waterfall is a formal method using top-down development, if the requirements are not well understood it might lead to inefficient software system. Also the process is time-consuming as each stage is dependent on the



previous stages. The main reason for this approach is that it provides clear points to check progress of the project.

Cusumano and Smith (1995) show that the waterfall model works reasonably well in stable problem domains using an incremental approach starting from design details and proceed to the end of projects but it is not a good framework for controlling the development process which involves many uncertainties to resolve changes in the design. For instance, if the developer tries to make changes in parts of the product or even to add a feature, then the project may end up in failure (Cusumano and Smith 1995). The waterfall model may incur high costs for small teams and projects (Karlm 2006). This model would not be suitable for this thesis as little is known about self-care decision making, there is a need to refine the understanding of self-care decision making and for testing the design using an iterative process.

#### ***2.5.1.2 Incremental Process Model/ Iterative Model***

This model (Shewhart 1939) goes through several iterations of the software development life cycle resulting in an iteration release at the end of each iteration. This model overcomes some of the limitations of the waterfall model by providing faster results and greater flexibility as the development goes through several iterations the system keeps evolving. Although an iterative process helps to refine requirements and design, it is not very clear when to stop iterations or to break up work into manageable phases (Cusumano and Smith 1995; Osorio et al. 2011). Iterative approaches have also been applied in the design of decision aids as shown in the CISDA process.

#### ***2.5.1.3 Evolutionary Process Models***

This model adopts Waterfall and the Incremental Process model. The model uses prototypes early in the design for highlighting the potential problem areas through early evaluation of

the development phase. The spiral model is a realistic approach to the development of large-scale systems as it evolves through the process but provides advanced versions for the users to gather experience and gradually firm up their requirements of the subsequent system. Although this model takes an account of performance relevant characteristics, it provides limited guidance to software performance engineering (Schmietendorf et al., 2002) and to the number of iterations needed.

#### ***2.5.1.4 Unified Process Models***

The unified software development process by Jacobson et al., (1999) discusses the need for a use-case driven, architecture-centric model using an iterative and incremental software process. The goal is to describe the customer's view of the system in terms of the use-cases and suggests a process flow in an iterative and incremental way. This model uses object-oriented analysis (OOA), design (OOD), and programming (OOP) and UML (Unified Modelling Language) to reduce the complexity of a software system. Unified process supports in modelling individual parts of the process, actions, and processes and in translating design into programming. OO is mainly aimed towards the OOA design and data modelling. For instance, OOA uses UML to describe the structural and behavioural properties using various visual models for creating software based on OOD. OOD is translated into programming or software through OOP. Hence it can aid in implementation using OOP and design integration OOA and OOD.

A review of OO analysis and design methodologies by Fichman and Kemerer (1992) shows that: (1) OOD does not provide systems partitioning like decomposition of large systems involving multiple teams for rigorously defined process of subsequent reintegration of the components and (2) OO does not provide a specific model for describing end to end global process.

Although the prescriptive software process models suggest somewhat different process flow, they all perform the same set of generic activities: communication, planning, modelling, construction, and deployment (Pressman 2005). These are mainly software focused resulting in programs, documents, and data produced from the framework activities.

### **2.5.2 Agile Development**

Agile development process is based on incremental and iterative development aimed at customer satisfaction and early incremental delivery of software; small, highly motivated project teams; informal methods; and minimal software engineering and development (Pressman 2005). The development of the software life cycle is divided into smaller feature sets called “iterations”. Each iteration starts with user requirements captured in descriptive stories and written on index cards. These user stories provide a high-level definition of a requirement with information for the developers to implement within a reasonable timescale. Although this process is highly successful there are some issues (Petersen and Wohlin 2009):

- If iterations are released more frequently then there will be an increase in the maintenance efforts.
- Agile methods do not scale well due to the planning of the technical structure and matching it against the time-line.
- There is little focus on the architecture leading to wrong design decisions.

### **2.5.3 Human-Computer Interaction (HCI) Methods**

The above software engineering methodologies like Agile or waterfall models can no longer be used on their own as they lack methodologies used for analysing human activities in specific work context. This section provides an overview of HCI methods to inform the design and development of self-care decision making tools for achieving the thesis aims. In broad terms, the review begins with the widest focus on a ‘system’ and then homes in on the

individual ‘user’. While a User-Centred Approach implies focus on one person using one computer (in one location for one task), most HCI practitioners accept that the term ‘user’ is synonymous with stakeholder and that different people might make use (or be affected) by the system in different ways. For the purpose of this thesis, UCD takes this more catholic interpretation.

### ***2.5.3.1 Socio-Technical Systems (STS)***

A STS design approach comprises of a technical level (hardware and software), a human level (stakeholders, maintenance agents, operators, designers) and an organisational level (a set of rules, policies, interactions governing different actions, and more) (Belmonte et al 2011; Sommerville et al 2012; Long 2013). STS design approaches have been applied for many years in complex domains such as transportation, military, and healthcare. In general, the approaches begin with the need to define and scope the system, its components and stakeholders, and then to provide minimal critical specifications of support for this system (Trist and Bamforth, 1951; Mumford, 2006; Chern, 1986). A more extensive review on STS is provided by Mumford (2006). The majority of STS approaches focus on the management of change in large systems and, as such, are outside the scope of this thesis. However, a parallel school of thought has arisen around the approach of Cognitive Work Analysis (CWA) (Rasmussen, Pejtersen & Goodstein 1994; Vicente 1999).

While it is not strictly a sociotechnical systems approach to design, CWA provides an approach which defines system components and stakeholders, and the relations between these and the overall purpose of the system. It also lends itself to the need to provide minimal critical specification (Chern, 1986) through its emphasis on designing how a system *might* appear rather than how it *should* appear. An added benefit of CWA, which is utilised in this

thesis, is that it provides a range of different views of the system under consideration, with each view emphasising different perspectives on how the system operates.

CWA is used to capture user goals in a given work environment to gain insight into work domains. CWA is an analytic framework which is widely used due to its formative nature for analysing human-system integration, where the analysis simply describes the requirement the system needs to satisfy to achieve its functional purpose (Sanderson and Naikar 2000).

#### ***2.5.3.2 Soft Systems Methodology (SSM)***

This approach focuses on dealing with human complexity for understanding the problem from different perceptions of the stakeholders (Checkland 1981; Checkland & Scholes, 1990). This approach is useful in identifying loosely specified problem and modelling by representing processes as nodes in a diagram and to indicate how process follows from one process to another. Complex processes are decomposed into sub-processes for identifying key attributes of each process. Although SSM provides support in reducing human complexity there is a lack of guidance on choosing what to model (Kingston 1995). Moreover, SSM does not consider technical implementation.

#### ***2.5.3.3 Participatory Design***

This process encompasses the whole design cycle for the design of the workplace, where users are involved as members of the design team (Dix et al., 2003). Users provide input by analysing the organizational requirements and planning appropriate social and technical structures (Preece et al., 1994).

#### ***2.5.3.4 Ethnographic Methods***

Here the focus is on gathering user's perspective using observations, interviews, and questionnaires for studying their actual work practice in their actual working environment,

to discover what users do and why from the user's perspectives. These studies help in examining social and cultural patterns and meaning in the institutions, communities, and other social settings (Schensul et al., 1999). Ethnographic methods help in usability studies and in injecting the users' perspectives into the design of the project (Helander 2014).

#### ***2.5.3.5 User-Centred Design (UCD)***

UCD provides an iterative design process by focusing on the 'people', 'work', and 'environment'. The studies in Chapter 2 have applied User-centred design for the development of PtDAs. User-centred design (Norman and Draper 1986) is based on the context of the users, their work and their environment. UCD lie in several areas of basic and applied research such as:

- Cognitive and social psychology.
- Human factors and ergonomics.
- STS, work, industrial and occupational psychology.
- Engineering and organisational behaviour.

There are numerous methods for implementing the approach like the usage-centred design (Constantine and Lockwood 2003) based on the ISO 13407 standard for specifying User-Centred Design (UCD) or the Gould and Lewis (1985) design process for interactive systems. The Human-centred design for interactive systems ISO 13407 has been revised by ISO 9241-210:2010. According to ISO 9241, the fundamental principles for a human-centred design process for interactive systems are:

- Explicit understanding of users, tasks and environments.
- Active involvement of users throughout the design and development.
- Refinement of the design using a user-centred evaluation.
- Following an iterative process.

- Address the whole user experience.
- Use multidisciplinary skills and perspectives.
- Design software solutions and
- Evaluate designs against the requirements

## **2.6 Problems in Current Development Approaches and Research Implications**

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Although Review Study I revealed more decision aids for self-care, there is less literature on actually designing self-care decision aids as it is quite complex. This section highlights the challenges in the current approaches.

### **2.6.1 Understanding Decision Making for Design**

Literature reviews and Table 2.5 (Akl et al., 2007; Smith et al 2009; Guo et al., 2015; Sunyaev and Chomyi 2012; Ahmed 2011; Aki et al., 2007; Zao et al., 2008; Ubbink et al., 2008; Carroll et al., 2013; Anchala et al., 2013), show the need for requirement analysis but there is less evidence on what decisions patient's make or how the decisions are made. Riegel et al. (2009) states that self-management involves decision making but it is not clear what decisions patients face as the real decision making requirements of elderly patients at home are less represented in clinical trials (Herrera et al 2010).

Naturalistic Decision Making (NDM) researchers studied firefighters, military commanders and physicians to understand how people actually make decisions in natural environments or in simulations (Zsombok and Klein 2014). Their studies show that people use experience to make decisions and that the processes and strategies differ from that revealed in traditional decision research. For example, in natural environments decision makers are more concerned

about the sizing up of the situation and invigorating their situation awareness through feedback, rather than developing and comparing multiple options with one another. In another study, it is found that the outcomes of the past actions can influence or affect the future actions, hence one 'decision' may in fact be a sequence of decisions, each influencing the next decision (Ranyard et al., 1997). It is also known that during decision making people often ask for help, advice or support from family, friends or experts, mathematical models on their own, will no longer be the only tool capable of solving decision problems (Bouyssou 2013).

Decision theories like prospect theory assume decision making as a mechanical procedure combining rules, probabilities and outcome values. The current approaches are based on either algorithms or implicit assumptions of designers. Although the papers have mentioned about decision theories there is less evidence on the application of the theories in the design. These approaches can be applicable for specific situations or decision problems. For example, Dowding et al., (2004) uses decision trees for providing users with information regarding the probability of different outcomes occurring in Benign Prostatic Hyperplasia. These models can soon become invalid or inefficient if the rules change in the decision trees. For this reason, normative approaches that specifically deal with temporally ordered actions would result in patient being ill prepared to cope with ambiguity, uncertainty or unanticipated events (Naikar and Lintern 2002). Consequently, there have been few studies examining how patients' make self-care decisions (O'Connor 2003; Thorne 2003; and Haas 2006).

### **2.6.2 System-Based View**

The traditional approach to software development is based on developing raw information on the state of the system based on the designer's anticipation of required information needed for supporting decision making. For example, the development of system might begin with



a description of functional requirements/ needs analysis, design and development in terms of the type of data required and developing raw information on the state of the system, that is based on the designer's anticipation of required information needed for supporting decision making (Akl et al., 2007; Smith et al 2009; Guo et al., 2015; Sunyaev and Chomyi 2012; Ahmed 2011; Aki et al., 2007; Zao et al., 2008; Ubbink et al., 2008; Carroll et al., 2013; Anchala et al., 2013). However, human capabilities and expectations do not always match these requirements (Booher 2003). For instance, it is essential to ensure that the interface in the system, does not cause the user to make errors at critical times or to overload the user (Booher 2003).

Whereas, the normative approaches shown in Table 2.5 (Dowding et al., 2004; Woo et al., 2014; Hommersom et al., 2013), focus on how the system currently performs or how it should perform (like do 'X' or 'Y'). To address this a formative approach is required to not only focus on the system constraints but also to help designers exhaustively, but concisely, describe the system under analysis.

Moreover, the design of user interfaces for information or situation display plays a crucial role for successful sense making and decision making in unstructured and unforeseen circumstances, particularly in systems incorporating decision support (Oosthuizen and Pretorius 2013). Designers of interfaces for such systems use a variety of approaches to describe systems function and the cognitive and social aspects of humans from an ecological point of view (Satake et al., 2002, Oosthuizen and Pretorius 2013). Section 1.2 has identified five dimensions of complexities, so a system-based approach is needed to model these and the constraints that shape patient's action in their environment to inform the designers of the possible choices and to explore new and different ways of supporting decisions rather than building on current practices. For example, the ecological approach gives a system view to understand the difficulties or decision problems experienced by older individuals in the

context of performing healthcare tasks (e.g., the decision-making processes involved taking medication) (Fisk and Rogers 1997). This view of the system helps in the integration of the information across various levels of abstraction to support knowledge-based reasoning and in extending or compensating the cognitive abilities of the user, to provide meaningful support for the patient, independent of the task and reduce the cognitive work load.

The frameworks and models (like IPDAS, CCM and Ottawa) suggest the need to consider the environments, systems and humans. As self-management is comprised of multiple components, accompanied by related services, understanding the components in the systems and how they work forms a key in the design of decision aids. This implies that there is a need to incorporate approaches to represent the work systems including the functions of technical equipment, resources and preferences, together with the functional structural requirements of the work organisation and management (Woods and Hollnagel 1983). The systems perspective would promote identification of the functional structure of the work domain, the outcomes that needs to be achieved, human work roles, and a collaborative process to facilitate the transactions between people and the cognitive tasks and strategies used in decision making.

### **2.6.3 Human Cognition**

More than half of the chronic disease patients are above the age of 70 (WHO) living with one or more chronic illness. Older adults experience many age-related changes including changes in the sensory, motor and cognitive functioning (Stronge et al., 2007). For instance, aging involves loss of ‘episodic’ memory (forget whether they took medicine or not), but maintenance of ‘semantic’ memory (would remember the medicine that treated their problem). Aging also reduces the processing capacity i.e., understanding complicated medical instructions (Rogers and Fisk 2001). These cognitive changes can get elders into

negative cycle (like recognizing the decline in their abilities) leading them to avoid intellectually demanding tasks (Fisk and Rogers 1997). Clarke et al (2004), specifies that people use different approaches in decision making: Scramblers process is where users are forced to respond to a serious injury or illness; reluctant consenters process where users are pushed to make a change in health care arrangements by relatives or health care professionals; Wake-up call decision process is where users chose to make new living arrangements in response to a near crisis that could have resulted in serious injury; and Advance planners decision process where users research their decision alternatives and make plans. To address these changes, study by Mynatt (2004) suggests that support technologies for older adults need to include:

- Compensating for physical decline (controls are typically difficult to see, operate, and remember)
- Aiding recall of past actions - for ‘episodic’ memory recall which can hinder older adults from completing tasks when interrupted or distracted.
- Supporting awareness – involving family members in the care.

Zao et al., (2008) also specifies the hardships encountered by the elderly patients including: memory degeneration (e.g., missing medicine doses); information shortage (e.g., age and multiple conditions could lead to lack of information on medicine and/ diet); information management (e.g., forget doctor’s advice); and emergency care (e.g., lack of symptoms recognition and appropriate action). With these real-life challenges, it is not possible to codify all the above in a set of rules and produces (Klein 2009).

#### **2.6.4 Usability and Usefulness**

Most of the studies in the literature review focus on system usability, and check whether the systems are ease to use for the users. Although usability is very important there is also a need

to support users in their decision making process. As decision making involves different types of decision process, most of the patient decision making research is focused on specific treatment options or preferences, or informed consent where the problem choices are discrete based on static choices (Dickson et al., 2008). Hence the interventions are mostly designed based on the understanding of decision making on an episodic, acute healthcare model (Hubbard 2008; McCaffery 2007; O'Connor et al., 2004).

## 2.7 Gap Analysis – Literature Review Studies

There is a lack of uniformity in the ways in which self-care decision aids are designed. Based on the implications and problems discussed above, this section provides the gaps identified.

*Table 2.6. Gaps and Thesis Chapters*

<b>Gaps</b>	<b>Thesis Chapter</b>
Review Study I and II shows that the decision support is mainly rule-based or provides general information to specific problems. Each and every patient is different so support for self-care management decision making should be tailored, this remains largely unexplored (Bekker et al., 1999).	Chapter 5 and 6 uses a UCD approach to understand patients and self-care decisions for software requirements specifications.
Review Study II and IV shows little evidence in applying the theory for the design of decision aids. Section 1.1 and 2.6 shows everyday decision making is complex hence it is not possible to codify all the possibilities into a set of rules and produces, (Klein 2009) little attention has been paid to elicit the underlying assumptions and perspectives in dealing with complex issues (Jarupathirun et al., 2007).	Chapter 6 uses Naturalistic decision making (NDM) to capture patient's decision making experience to overcome the complexities in sections 1.1 and 2.6.
Section 1.1, Table 2.3, IPDAS, MRC and Ottawa framework specify the need for modelling to understand and provide a step-by-step approach for supporting decision making as patients use different decision strategies and courses of actions.	Chapters 6 applies NDM to describe decision making. Chapter 7 helps to analyse the decision making to capture a system-view for understanding the various interactions, people and decision strategies.
Review Study IV shows that most of the studies follow the traditional approaches for the design of complex systems: like requirements gathering, design, development and testing. Although the literature review studies have used frameworks like MRC, CCM and Ottawa, there is a lack of guidelines and process.	Chapter 3 proposes systems based template and a systematic approach for the design and development of self-care decision aids. Chapters 4-10 provide guidelines and instructions for the design and development.

Although previous interventions have met some success, Table 2.6 offers clear insights into the implications, not only the shortcomings in fully addressing everyday self-management and decision needs, but also how systems can overcome the gaps through re-thinking the current approaches using literature review.

## **2.8 Chapter Summary**

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This studies provides a summary of different types of decision aids and development process. Stacey (2011) shows that decision aids can increase people's involvement in reviewing treatment options, improves patient's knowledge of treatments, lowers decisional conflict between patient and consultant, and leads to realistic perceptions of outcomes. Understanding decision making based on patient's input would not provide comprehensive knowledge on the decision making process; hence it is essential to involve health professionals like doctors to further understand decision making process. There is a need for designs which better reflect "how patients make decisions" rather than "how should patients make decisions". This gap can be realized by understanding the following:

- First, the decision need and the decision making process of the patients using theory.
- Second, by employing a framework for modelling actual decision making process.

These reinforce the statement 'we require quality research to guide and evaluate this (interventions) and the development of novel patient-centred interventions to facilitate informed choice and optimal adherence' (Horne et al., 2005 page 20).

## Chapter 3 CHRONIC ILLNESS SELF-CARE DECISION AID (CISDA)

### FRAMEWORK

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*“...projects fail because they do not recognise the social and organisational complexity of the environment in which the systems are deployed. The consequences of this are unstable requirements, poor systems design and user interfaces that are inefficient and ineffective. All of these generate change during development, which leads to delays in the delivery of the system, and to a delivered system that does not reflect the ways that different stakeholders work” (Baxter and Sommerville 2011 page 12)*

This chapter addresses the thesis aims and research question 3: “how can we design decision aids to support everyday self-care decisions?” by proposing the Chronic Illness Self-care Decision Aid (CISDA) six-phased design process using an evidence based, user-centred design approach.

### 3.1 Introduction

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Healthcare is a complex ecosystem which can be seen as an elaborate “interwoven tapestry of finest legacy threads together with numerous patched weavings in the 20<sup>th</sup> and 21<sup>st</sup> centuries” driven by technology (Larson 2014, page - 153). However, the “patch” approach has reached its limitations. Reconceptualization and integration of emerging technology constituents are critical towards holistic thinking and design (Trist 1950) which is inherent in the sociotechnical systems approach and allows the consideration of changing people, technology, work organization and the human environment. The outcome of considering these in design as suggested by the frameworks (e.g., IPDAS, CCM), ought to be better for understanding how humans, technology, environment, social and organizational factors affect the ways work is done and technology are used for the design of PtDAs (Baxter and

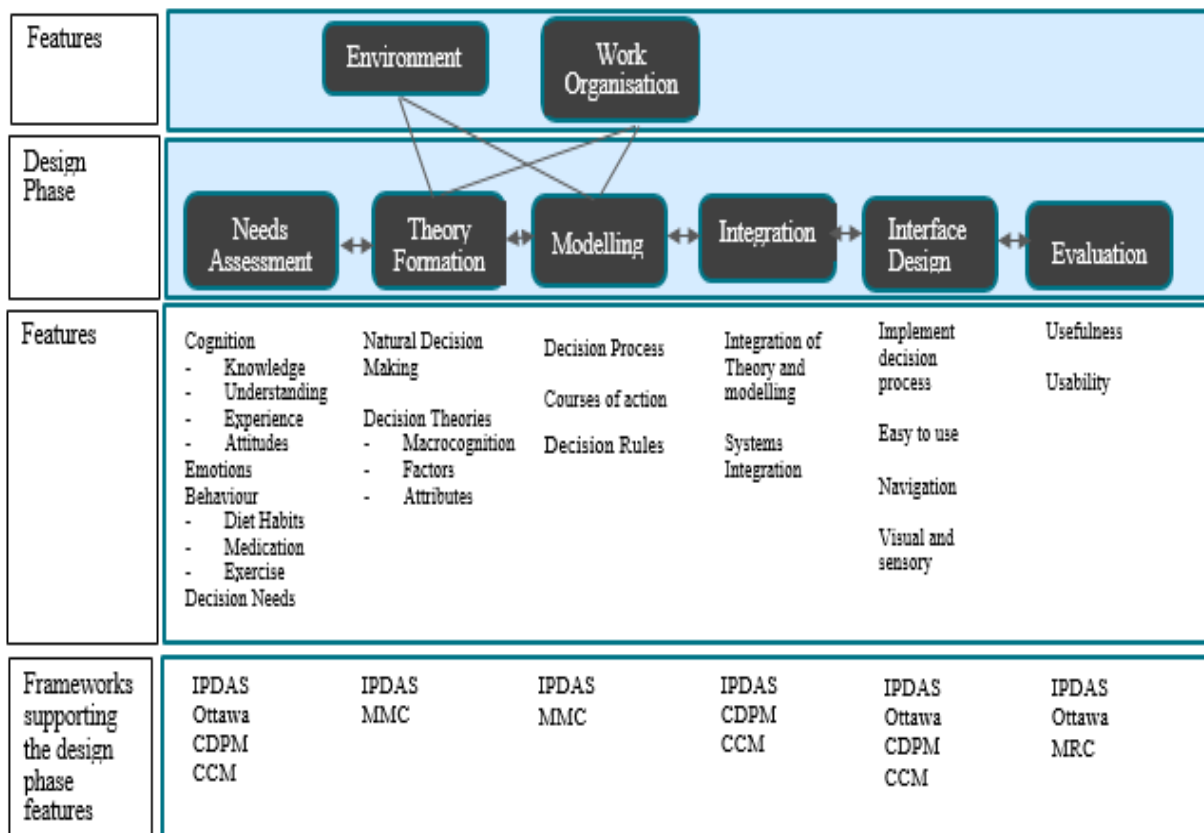
Sommerville 2011). Moreover, it is also essential to understand the constraints in the work domain, rather than the task procedures to support unanticipated events as the requirements for developing home-based systems are not the same as workplace systems (Baxter and Sommerville 2011). To provide guidance and structure for the development process, this chapter explores development methodologies to propose a development process and the methods needed for supporting each stage. For the design and development of this kind of a system, rather than finding new approaches to software engineering, as Baxter and Sommerville (2010) suggested, this section starts with existing software engineering process used in the Chapter 2.

### **3.2 System Development Criteria Based on Frameworks (e.g., IPDAS)**

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Literature review (Chapter 2) uses various software methods for design in spite of relevant international standards which are meant to cover user centred design of medical devices (such as ISO/IEC 62366). In this section, features which can be applied to support the design process (Figure 3.1) are explored. Most of the studies have used the models and frameworks shown in Table 2.2 for the design of decision aids as the standard engineering approach concentrates on the hardware, software, procedures and rules. Review Study 1 shows that the current PtDAs are focused on providing guidance for treatment decision or for vital signs monitoring to detect episodic events or access to doctors. This is mainly because patients are expected to be compliant or seek help from someone like health professionals as they are the experts (Thorne 2000, Tsoneva 2004). To overcome the complexities (Section 1.2) and problems (Section 2.6), rather than dictating the users based on visible and documented

evidence, patients need to be supported based on the aspects of their current work that are implicit based on actual patient experiences.



*Figure 3.1 Design Process Template for Supporting Self-care Decision Making*

The design process (Section 2.8) shows the need to consider humans, environment/ context, healthcare organization and the technology. The complexities and the problems (Sections 2.1 and 2.6) insists on the need to provide a system-based approach. Figure 3.1 draws on that knowledge from Chapter 2 to organize the criteria derived from the existing models (IPDAS, MRC, CCM) into relevant groups like in case of theory formation or modelling. Figure 3.1 shows all the criteria in the context of design process. This template divides the development process into various activity areas onto which the development process may be mapped. The arrows in Figure 3.1 indicates the flow of information from one stage to the other. As decision making is influenced by the people, environment and other factors, Figure 3.1 shows the flow



of information from the environment and healthcare organization into theory formation and modelling. The design process template emphasizes the need for two things:

- First, consider patients and other stakeholders throughout the development (understand needs, roles and tasks of individuals).
- Second, provide a system-level view to consider human, technology, environment, decision process, and healthcare organization.

Table 2.1 and Table 2.2 (Chapter 2) specifies the criteria and the design requirements that can be used for the design of systems to support decision making.

**Needs Assessment:** This phase provides solid foundation for understanding user experiences and needs for decision support. In addition to needs, it is also essential to understand the age-related physical and cognitive abilities to provide appropriate support (Rogers and Fisk 2001; Preece et al., 1994). For example, it is essential to understand the following:

- Cognitions – including patient’s knowledge, understanding, experience and attitudes
- Emotions at the time of decision making
- Behaviours – like diet habits, medication adherence, physical activity
- Decision needs based on patient experiences
- User context
- Visual, sensory and physical challenges faced by patients.

In Chapter 2, the review studies (I and III) have used patient-centred or user-centred approach for needs assessment to gather patient’s knowledge, experience, abilities, emotions, cognitions and behaviours using various human factors methods like: interviews; literature review; focus groups; and ethnography.

**Theory Formation:** Although there are several theories to understand decision making, the first point is to find out how patient actually make decisions and what is needed for

supporting decision making. The problems in understanding decision making and human cognition emphasise the need for studying natural decision process rather than applying mathematical models (2.6). For decision making theory formation, first understanding of patient's decision making is essential based on patient's stories or case scenarios. In the review Table 2.4 (Chapter 2) shows multi-attribute, Bayesian and other theories are applied in the design process to define how decision making needs are supported. This again involves a patient/ user-centred approach as undertaken by many studies in Chapter 2. Naturalistic Decision Making (NDM) theory is also applied (Table 2.4) to show how decision making is currently performed using macrocognition or patient's mental models. Moreover, NDM shares the same characteristics of decisions dealing with uncertainty and ambiguity.

**Modelling:** According to Norman and Draper (1986), the users develop a mental model of the system so capturing the mental model and converting to the design model would enable the designer to provide better support. Modelling would also help to capture the different decision processes used by the decision makers as specified by Clarke et al (2004).

Table 2.4 (Chapter 2) shows various modelling techniques used in the current decision aids including: UCD methods like cognitive task analysis, user task analysis; UML models like use cases, user scenarios, stories and; algorithm based approaches. Some of the studies have also provided system-level view of the decision aids by partitioning the system into components and sub-components using STS approaches. This view would help to address the complexities and problems raised earlier and for gaining a systems-based view of the system.

**Integration:** Patients use various information sources and equipment (e.g., weighing scale) which needs to be integrated into the system. The design process includes environment (including sensors to detect the environment and context), healthcare organization (including

people, resources) and modelling techniques that needs to be integrated into the healthcare systems (Esquivel et al., 2012; Johnston et al., 2011). Integration in this thesis is more focused on translating system-based approaches (like STS) into software interface design and development. In the Chapter 2 review, some of the studies used UML use cases and scenarios rather than a systems-based approach for modelling hence, there has been less focus on integration. As suggested in section 2.5 application of ecological approach would help in conducting work analysis by an explicit analysis of the constraints that the environment imposes on action (Zsombok & Klein 2014). Using this the designers could ensure that the content and structure of the interface is compatible with environment constraints.

**Interface Design:** Providing an intelligent, understandable interface that bridges the gap between people and systems (Norman & Draper 1986). The way the information is presented and the context in which the information is provide can cause significant effect in the success of the system (Fisk and Rogers 1997). As mentioned in Table 2.4 the decision support systems need to take into account HCI elements like the content, presentation and layout. The decision aid designers have used an iterative patient/ user-centred approach with the patients for evaluating the designs. This helps in addressing the usability problems.

**Context/ Environment:** An analysis of the human-environment in which decisions are made is needed to provide environmental support for minimizing the cognitive demands (e.g., external cues or strategies used by patients to enhance medication adherence, like, combining medication intake with meal) (Rogers and Fisk 2001). Context-aware sensors have been used to detect the context and environment, so there is a need to consider these using a system-based approach to integrate into the design process as shown in the Design Process Template. For instance, STS approach considers environment, people, organization and the technology.

**Healthcare Organization:** Medical decision making involves interaction with various people (nurse, doctors and family), equipment, procedures and environments in everyday living. An understanding of these factors could significantly improve the effectiveness of the system (Sanders and McCormick 1987; Carayon 2011). Although stakeholders are considered using UCD approach, their role in the system is not defined in the development. System-based approach like STS should help to integrate the roles of the stakeholders in the system.

**Evaluation:** Review and testing by the users and subject matter experts. Review studies (Chapter 2) shows various evaluation undertaken for testing decision aids using long-term trials, verification of the aids with subject matter experts, assessing effectiveness, ease of use, navigation, and usability testing. The studies explored in Table 2.4 (Chapter 2) have used various strategies for evaluating the decision aid through: verification, acceptability and usability test and long-term trials using patient/ user-centred approaches.

### 3.3 System and Software Development Approach for the Thesis

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Section 1.2 has identified five dimensions of complexities and section 2.7 shows the problems in current approaches in four dimensions including: the need for understanding decision making, system-based view, addressing the human cognition, usability and usefulness. These complexity creates challenges to the designer in translating user's mental model of the system into the design model (Norman and Draper 1986). To address these complexities, problems in current approaches, requirements suggested for chronic disease management and decision aids, there is a need to consider the humans, theory, environment,

organization and the system as a whole, that is the physical, cognitive and psychosocial system interactions. Some of the considerations that need to be made for the choice of methods for this thesis are as follows:

- i. Decision support systems in the Review Study III has been developed through the application of various theories like NDM, Multi-attribute and algorithm based approaches. NDM uses macro cognition to describe the real-time decision making. Hence, self-care is described as a naturalistic decision-making process occurring in real-world settings which include specific behaviours focused at maintaining health and well-being (Riegel and Dickson, 2008; Riegel et al., 2009).
- ii. Provide a systems-based approach for considering the human, environment, organization and technology in the design process.
- iii. Ensure that patient-centred design is undertaken in the design process for verification and design.

The traditional approaches like the Waterfall model, iterative and evolutionary approaches are more technology focused so provide little support in theory formation and modelling as there are no defined methods. Agile as mentioned in section 3.2 seems to lack support for the high-level view/ architecture of the system. Participatory process, Ethnography and Soft Systems approach seems to provide some support in the early stages of the development. Unified process uses various UML notations to support the development process and is mainly used for software analysis and design. Although UML provides support for most of the development face, UML does not consider the human factors or the ergonomics needed for the design. UML is a software engineering process aimed at describing the structural and behavioural properties of the software being created.

The UCD approach provides various methods for needs assessment, modelling, work organization, interface design and evaluation. STS also specifies various design approaches

like Cognitive Work Analysis (CWA) and Soft-systems Methodology for theory formation, modelling, environment and work organization analysis. CWA addresses the systems-based perspective and is successfully applied in a number of military systems to support decision making (Burns et al 2000, Naikar et al., 2003). CWA also provides an ecological perspective through abstraction hierarchy to define the system boundaries. CWA is made up of 5 phases and each of these phases describe the system in terms of its constraints, models the system purposes, functions, components and capabilities thereby addressing the complexities involved in supporting decisions. CWA is useful in analysing human activities for supporting human cognition (section 2.6) in specific work context by focusing on their functional structure of the domain, organizational relationships, cognitive, and ergonomic attributes of actors. But STS provides less support to interface design and evaluation when compared to UCD and HCI.

As UCD has intellectual roots from human factors and ergonomics, and STS design, STS methods can be applied in UCD for supporting analysis and modelling decision making. As mentioned in Chapter 1 there is a gap between the ‘humans’ and the ‘system’ and there is a need to consider the ‘people’, ‘work’, ‘environment’ and ‘technology’ (Chapter 2) that can be linked and bridged using an Iterative, UCD design approach with the application of STS methods for modelling and integrating human, environment, organization and technology.

Using UCD ISO13407, the problems identified in the existing approaches such as understanding decision making, usability and usefulness of the system can be addressed. Application of NDM to help in describing decision making and CWA for a systems-based perspective to address the complexities. Hori et al., (2001) integrated STS systems life cycle method like CWA with Human-Centred Design standards ISO13407. This study shows that integrating this research provided great benefits to expand and improve the ISO concept for

industrial systems, and to give a concrete methodological perspective for systems engineering and facilitate STS technology and knowledge transfer to practical design.

### **3.4 Chronic Illness Self-care Decision Aid (CISDA) Development Framework**

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As the complexities and problems identified in the current approaches can neither be removed nor hidden, as failure to address these would result in high risk (Hollnagel 1992). In addition to these, the various cultural, social, physical and cognitive characteristics magnify the complexity. Due to this and the complexity involved in supporting everyday decision making there is little guidance for the design of patient decision aids.

The design process template (Figure 3.1) provides a common structure needed for the overall decision aid development process based on the criteria derived from the models and frameworks for decision support (IPDAS and Ottawa), chronic disease management (CCM, Ontario's CDPM) and the design of complex interventions (MRC). As shown in Figure 3.1 the design process template divides the development process into a number of distinct areas needed for development. Chapter 2 shows that (1) none of the existing systems design approaches provide full support to address these criteria and (2) various methods have been used for modelling like UML, use cases, task analysis but little guidance exists on usage of theory, its application in modelling and design of decision support systems. Therefore, a systematic development framework is needed to break down the complexity in the design to better understand user experience and decision making. Otherwise software will just be developed based on normative approach that is instructing the patients to do this or that and not supporting the patients in their self-management. As the design process template provides

the different phases along with the features needed for the development of self-care decision making, it does not represent a UCD or patient-centered, iterative process to help developers in the development of the system.

Although the output from one phase forms as an input to another phase, in reality any change in the modelling phase can also involve revalidation using needs assessment. Moreover, as the tools for developing incremental or iterative process have increased over the years, Figure 3.2 addresses this so that system can be developed incrementally using feedback, design and prototyping to ensure usability and user-friendliness. The proposed CISDA process supports the recommendations made in the literature for improving complex technologies (El-Gayar et al., 2013; Johnston et al., 2011; Esquivel et al., 2012; Hori et al., 2001). For example, El-Gayar (2013) study highlights the need to apply user-centred and socio-technical design principles to bridge the gaps in ease of use, timely feedback, integration with healthcare information systems and decision support. In addition to the main stages for the development, Figure 3.2 also highlights the features/ characteristics that are needed in those stages based on Figure 3.1 to guide the designers in the development of DAs. The features/ characteristics provide guidelines for the developers and can be extended or reduced depending on the project requirements. The CISDA process with six distinct phases reemphasises the need for supporting self-care decision making by understanding patient's needs and decision making (as opposed to simply encouraging them to comply with rules) to support O'Connors (1989) view of good decision making by helping patients make an effective, informed decision that is consistent with the decision makers' values and behaviourally implemented.

CISDA does not propose a new design process but uses a UCD approach for the design and development of decision aids based on IPDAS, CCM, Ottawa, Ontario's CDPM and the MRC framework. CISDA gives a concrete methodological perspective for Systems Engineering and to facilitate STS technology and knowledge transfer to practical design



through the application of the UCD approach. CISDA is concerned with the design of the system from the user's perspective involving techniques (like Interviews, Focus groups, CWA, NDM).

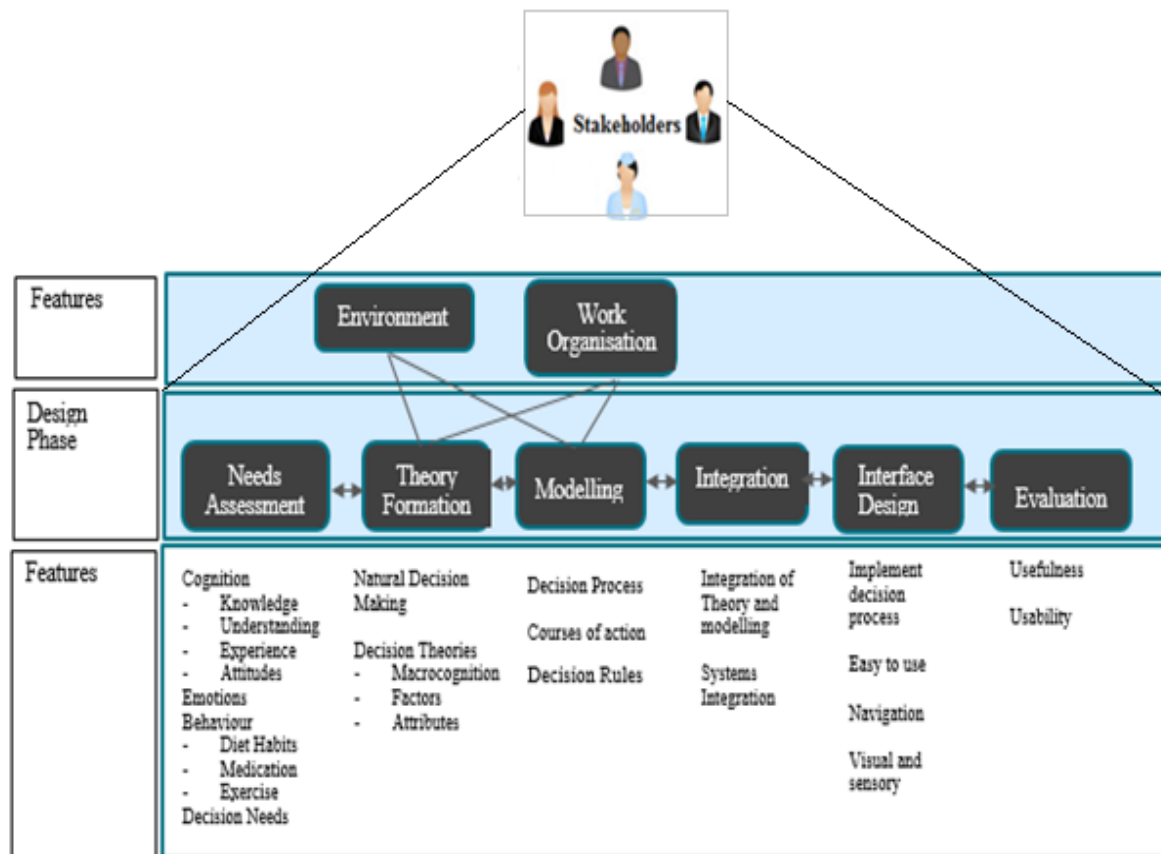


Figure 3.2 Chronic Illness Self-care Decision Aid (CISDA) Development Process

The ultimate aim of this thesis and the CISDA process as quoted in Chapter 1 is:

*To formulate a process for the design and development of self-care decision support aids as well as to provide guidelines for analysing patient decision making and integration into design.*

To address the thesis aims, the CISDA process provides a systematic approach for the design and development using a 6 phased approach. Each stage in the CISDA process is described

using cardiovascular disease self-care decision making as the case study in Chapters 5-10.

Each phase chapters begin with a set of guidelines/ overview for the developers including:

- Overview
- Composition
- Methods
- Participants
- Outcomes
- Quality Criteria
- External Dependencies

### **3.5 Summary**

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Decision making is about people responding to constraints set by other people (like caregivers or doctors), their health conditions and the environment. Therefore, decision options are shaped by the context, environment and people. To understand this and the interactions between the various attributes in decision making, this thesis suggests that a system-level view is required for understanding self-care decision making as shown in the design process template (Figure 3.1). Therefore, there is a need to gain deeper insight into the nature of decision making in a ‘system’. Although there are some frameworks available for the development of self-care decision aids there is lack of a well-documented systematic design process. This section and the rest of this thesis, is aimed at providing guidance to designers and engineers for the implementation of self-care DAs.

The CISDA framework is similar to MRC but MRC is more focused on the trial of complex systems and CISDA focuses on the design and development of decision support system using a systematic six stage process to base on ‘how patients self-manage’ or ‘how patients make decisions’ or ‘how to develop tools for supporting decision making’. By presenting the CISDA process through a worked example (focusing on CVD patients Chapters 5 - 10), the aim is to not only illustrate how the process is applied but also highlights its purpose-specific features. This means that rather than having a disjoint between the user requirements analysis and software implementation, there is an auditable path from one to the other.

This thesis not only proposes the CISDA framework but also provides details of how the decision support systems can be prototyped in the following chapters. But before describing the design process, it is essential to identify the research methods needed for addressing the design requirements.

## Chapter 4 METHODS

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*“You can't just ask customers what they want and then try to give that to them. By the time you get it built, they'll want something new.” Steve Jobs*

The purpose of this chapter is to provide a brief overview of the research methods applied in the CISDA design process case studies (Chapters 5-10) for the development of a self-care decision support system mobile application. To explore this research questions, the thesis uses various research methods like: focus groups, questionnaire, interviews, case studies and testing. In addition to the research methods this chapter also provides highlights on the STS method CWA for modelling and UML for integration along with ethics for human participation. As the design process is applied to cardiovascular disease (CVD) support and decision making, the methods deal with CVD patients.

### 4.1 Introduction

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To explore the research questions for the thesis, exploratory and descriptive research methods are used. This combination should aid as guidelines for the CISDA process needs assessment, theory formation, modelling, integration, interface design and evaluation (Chapters 5-10) of self-care decision support system mobile application. Table 4.1 shows a mapping of the chapters with the research methods. The research process for meeting the study objectives was devised through a number of discussions with researchers' in the development of healthcare systems (Glenfield Hospitals Cardiac Research Group) and by reviewing the literature. According to Crotty (1998), there are a number of research methodologies which can be used to elicit information from people including: survey

research, experimental research, ethnography, grounded theory, heuristic inquiry, and action research.

*Table 4.1 Mapping of Methods with Thesis Chapter*

	Focus Groups	Interviews	Questionnaire	Case Scenario	CWA	UML	Testing
Needs Assessment Phase (Chapter 5)	√ (Section 5.4)		√ (Section 5.5)				
Theory Formation (Chapter 6)		√ (Section 6.4)	√ (Section 6.6)	√ (Section 6.4)			
Modelling (Chapter 7)					√ (Section 7.2)		√ (Section 7.4)
Integration (Chapter 8)					√ (Section 8.3)	√ (Section 8.3)	√ (Section 8.4)
Interface Design and Development (Chapter 9)			√ (Section 9.5)				√ (Section 9.6)
Evaluation (Chapter 10)		√ (Section 10.3 and 10.5)	√ (Sections 10.4, 10.5 and 10.6)	√ (Section 10.4 and 10.5)			√ (Sections 10.2 - 6)

For this study, survey research was the most appropriate to understand self-management needs, decision making process and to evaluate the design process for supporting self-management. This survey methodology allows data to be collected in a sample of subjects from a small, well-defined population and to make inferences about the study. In this research, focus group studies or interviews were used for preliminary information gathering followed by questionnaire for additional information gathering. In addition to data collection methods the thesis uses methods like case scenarios for Theory formation, CWA for modelling, UML for translating CWA to software specifications, and Testing CISDA Process and Usability.

## **4.2 Focus Group**

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Focus group discussion (Gibbs 1997, Cooper and Baber 2002) is an effective way to gather information in which small groups (5-12) of participants gather to discuss a specified topic or an issue (Wong 2008). Focus group studies have been used from initial exploration to requirements gathering and evaluation. In healthcare focus groups have been used to explore the health issues including: understanding of health risks, treatment preferences and impact on quality of life (Rasmussen 1987); reducing CVD risks (Wong 2008); and racial disparity in cardiac decision making (Kennelly 2001).

### **4.2.1 Conducting Focus Group**

Focus group sessions in this thesis were conducted in small groups of 5-12 participants. The focus groups have a fixed time of 45 minutes to 75 minutes. In the focus group a moderator conducts the focus group sessions by raising questions about a topic to the group and the group members exchange ideas and comments on each other's experiences or views using the focus group guide developed by the project team. A note-taker is usually present to assist the session and audio recording is carried out for later review and reporting (Chapter 5, Study I).

### **4.2.2 Participants**

The participants for this study involved older adults diagnosed with CVD attending various heart groups and heart clinics in the West Midlands and Cheshire, UK were approached for the study. The patients in the heart groups were given presentation of the thesis aims and objectives and were asked to sign-up for the study.

### **4.2.3 Study Setting**

The studies were conducted in rehabilitation clinics, public libraries, heart group meetings and physiotherapy class rooms. Data were collected from patients in the West Midlands and Cheshire in the UK. As the study uses UCD rapid, iterative process; the survey methods were carried at 4-6 month intervals from October 2010 to June 2015.

### **4.2.4 Types of questions**

The focus group sessions followed a semi-structured process for gaining in depth insight that may be harder to achieve using a structured process. The questions were open-ended like, “Tell us about your diet?” “What sort of decisions do you need to make?” (Section 5.4.2 Chapter 5). These questions were developed based on a literature review to identify self-management and decision making needs of patients. The questions for exploring were ordered in such a way to first explore the self-management experiences and then explore decision problems faced by patients in everyday life.

### **4.2.5 Analysing Data**

As the focus group used a semi-structured, open-ended questions, the preliminary data were analysed by grouping all the focus groups into a single cohort. The reasoning behind this decision was that the participants were recruited through local heart support groups and presented with a similar collection of symptoms and had similar experiences of self-management. Audio recordings from the focus group studies were decoded. The text-based data were analysed using priori coding approach, to identify the potential coding categories from the literature for self-management in terms of diet, medication and exercise, and then text-data are grouped into appropriate categories. Once the data were analysed the results were sent back to the focus group participants for reliability checking.

#### **4.2.6 Overcoming Drawbacks**

Some of the potential drawbacks of the focus group is that, in a group setting, some participants may hesitate to disclose certain information, and that there can be a polarization effect, in which respondent's opinions tend to coalesce (Neuman 2011). To overcome some of these drawbacks for patient participants, the following process were used:

a. Participants were given an initial presentation about this research at local heart support group meetings to recruit patients followed by a leaflet consisting of research aims, focus group meeting details, date and time.

b. Informed consent was obtained from participants and data collected from them were kept anonymous. Participants were also informed that they could withdraw from the study whenever they wished or could request to have any data generated from their responses withdrawn from subsequent analysis.

c. At the end of each focus group, summary of the discussions was given by the moderator to identify key concepts and messages that the members of the focus group agreed were important.

d. The study aims and objectives were clearly stated to the participants to encourage them to share their experiences. Participants mentioned that this study might help them to better manage their condition.

#### **4.2.7 Validity**

To ensure focus group data validity a follow-up study with questionnaires were conducted to gather personal input e.g., Appendix C, D and E. Moreover, the write-up of the focus group analysis was sent to all the participants for reliability checking.



## **4.3 Interviews**

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Interview method was used to gather direct information and feedback from the participants to understand decision making and to evaluate the support. Interview studies were mainly used with doctors to explore in detail their consultation process in supporting patient's decision making.

### **4.3.1 Conducting Interviews**

Interview sessions were conducted face-to-face at a time and location convenient for the participant. The interviews were carried out for 30 to 40 minutes. In the interview the interviewer presented information on the project and starts the session by raising questions about a topic to the participant. The participant's feedback was recorded using note taking.

### **4.3.2 Participants**

Doctors working in primary healthcare centres or private practices in the Leicester and Birmingham were contacted by email and telephone with a brief study description. Not more than one doctor from each practice was selected to avoid prior knowledge and models of practice. All the doctors have been actively involved in treating patients with CVD.

### **4.3.3 Study Setting**

The interviews were mainly conducted at GP practices.

#### **4.3.4 Types of questions**

Like the focus group sessions, interview studies followed a semi-structured process for gaining in depth insight that may be harder to achieve using structured process. Three interview studies have been conducted in this thesis.

First to understand how doctors help patients in their decision making (Section 6.4.3 Chapter 6). This study was conducted with the doctors over three-month period in April 2011. The questions in this study were open-ended like, “How do you evaluate the condition?” “Do you provide the options available for patients?” These questions were derived based on the consultation models discussed in the chapter to understand how doctor’s support patients in their decision making. The order of the questions also followed the consultation model process to gather details of what features are involved (e.g., what cues doctors considered for the decision problem).

Second for assessing the prototypes with doctors (section 10.4, Chapter 10). This study was conducted with the doctors over two-month period in February 2013. The doctors were shown the developed prototype to gather their impressions of the prototype.

Third for verifying patient’s decision making with doctors (section 10.6, Chapter 10). This study was conducted with the doctors over three-month period in January 2015. This study uses presentation of case scenarios developed based on the literature review of focus group studies.

#### **4.3.5 Analysing Data**

As the interview study used a semi-structured, open-ended questions, the preliminary data were analysed by grouping all the interview notes into a single cohort. The text-based data were analysed using coding approach based on literature (Section 6.3 Chapter 6) and then

text-data are grouped into appropriate categories. Once the data were analysed the results were sent back to the doctors for reliability check.

#### **4.3.6 Overcoming Drawbacks**

The duration and location were well notified to the participants. Interviews were conducted in a neutral, non-judgmental, approachable way to get participant's feedback.

#### **4.3.7 Validity**

To ensure interview study validity, the findings were emailed for verification. The interview studies in evaluation followed a questionnaire study to gather direct, unbiased feedback.

### **4.4 Questionnaire Study**

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Questionnaires are used to gain further understanding on the decision process and to gather feedback on the design and prototype. A questionnaire helps in quantifying the data needed for research. Research participants were assured of anonymity and confidentiality (as required by University ethics approval in section 4.9).

#### **4.4.1 Conducting Questionnaire Study**

In the CISDA process case studies (Chapters 5-10) interviews and/ focus group sessions were followed by a questionnaire survey to gain further insights into the needs assessment, decision making, interface design and evaluation process.

#### 4.4.2 Participants

As the questionnaire studies were carried out after to focus groups and interview studies, the participants for this study mainly included interview (4.3.2) and focus group study (4.2.2) participants. For the testing, participants included:

- **IT Professionals** - IT professionals in research labs from the University of Cambridge, IBM, Microsoft, and HP labs. Presentations were given to IT professionals and engineers interested in the topic at Industrial Engineering Conference, Dubai (2015).
- **Psychologists** - Psychologists from the University of Cambridge were involved to gather feedback on the CISDA process and the prototype support.

#### 4.4.3 Types of questions

In Chapter 5 (section 5.4), questionnaire study is used to gain further information on patient's medication knowledge. The selection and order of questions for this study is developed using Ottawa's decision support for medication to gather patient's knowledge on their regular medication. Patient's feedback is analysed as shown in the following section.

In Chapter 6 (section 6.6) questionnaire study is used to gather patient's decision making case scenarios. The selection and order of questions for this study was developed based on literature reviews and Ottawa decision support.

Chapter 9 (section 9.5) and Chapter 10, the perceived usefulness questionnaire study is used for understanding user perceptions on the interface design, questionnaires were developed inspired by the Technology Acceptance Model (TAM) (Davis 1989). The TAM model was used to determine the success of a system by gaining feedback on user acceptance of the system that is measured through perceived usefulness, perceived ease of use and attitudes towards system usage. As TAM is elaborate, the questionnaires were kept minimal to focus

on specific factors due to the constraints in time, age of the population and their disease. The studies used close-end questionnaire as shown in Appendix E.

In Chapter 9 (section 9.6) a questionnaire study was used to compare various design options for the user interface. This questionnaire used screenshots to show various designs.

In Chapter 10 (section 10.5, 10.6, 10.7) a questionnaire study was used for understanding patients', doctor's, and professional's perception on the prototype designed and CISDA process. This study questionnaire was also influenced by TAM.

#### **4.4.4 Analysing Data**

The collected questionnaire data were recorded in an excel spreadsheet. The goal of the analysis was to simply describe the data in a manageable way to see how many participant responses were received to provide a high-level summary of the data using summary statistics such as percentages or number of responses.

#### **4.4.5 Overcoming Drawbacks**

In order to minimize bias, the wording of the questions, categorization of the questions and the responses were discussed with a few patients before the study. Each of the questionnaires was given along with the study objectives including anonymity and confidentiality details. Participants were also given consent forms for participating in the study.

Some of the strategies used to enhance the response rate were as follows:

- a) Questions were structured in such a way that it was easy for participants to understand.
- b) The questionnaires followed a focus group session relating to the progress of the project so it motivated the participants to contribute to the study.

- c) The questionnaires were focused on a particular topic for ensuring sufficient information was there to examine, hence participants were not given too much information.

#### **4.4.6 Validity**

To ensure study validity, questionnaire was checked and edited for errors and omissions for consistency and completeness with participants and experts.

### **4.5 Case Scenarios/ Studies**

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Case study presentations are used in this thesis for understanding the consultation process (Chapter 6) with doctors and for pre and post-test testing (Chapter 10). Case studies helped to get a thorough understanding within a specific real-life situation.

#### **4.5.1 Choosing Cases**

Case studies for understanding the consultation process were based on focus group studies with patients and literature evidence. For example, in Chapter 6 (section 6.4.3) cases were formed based on the focus group studies in Chapter 5 (Study 1) and supporting evidence found from Lorig et al., (2012) self-management book and Expert Patient Program. Similarly, the case study for pre and post-test evaluation were formed based on the doctor's suggestions during interview discussion (Chapter 6) and patient experiences shared during focus groups.

### **4.5.2 Data Collection**

Data collection for gathering case scenarios to test the descriptive framework in Chapter 6 were based on a questionnaire as explained in section 4.4.

## **4.6 CWA for Decision Modelling**

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The CISDA framework uses STS methodology in the development process. As Cognitive Work Analysis (CWA) is a systems-based approach for the analysis, modelling, and design of complex sociotechnical systems, it is often presented as a *de facto* approach which leads to better design. Such a claim requires two forms of support. The first is to demonstrate an auditable process through a design is arrived at from the CWA. The second is to compare designs produced through this approach with designs developed through other approaches. This thesis focuses on the first of these forms of support.

### **4.6.1 Why CWA?**

As decisions are made in dynamic complex environments, it is essential to understand the constraints in the work domain, rather than the task procedures to support unanticipated events. Development of decision aids (DAs) might begin with description of functional requirements, in terms of the type of data required, and then consider non-functional requirements of system operation. However, human capabilities and expectations do not always match these requirements (Booher 2003). For instance, it is essential to ensure that the interface in the system, does not cause the user to make errors at critical times or to overload the user (Booher 2003). Thus, understanding human factors in the design of computer interface becomes important. For this reason CWA was found to be useful to

consider the situation and to examine human decision making processes (Dalingier & Ley 2011).

#### **4.6.2 Application of CWA for Decision Support**

In general, applications of CWA have focused on experts in complex domains, such as command and control (Naikar and Sanderson 2001; Chin et al., 1999) or process control (Vicente 1999). In the medical domain, CWA has been applied to healthcare systems for 20 years to gain a deep understanding of the structures of system (Jiancaro et al., 2013).

- Patient monitoring (Sanderson et al., 2004)
- Clinical displays to effectively support clinicians (Effken et al 2001)
- Intensive care units (Miller 2004)
- Telerriage (Burns et al., 2008)
- Develop an assistive device to improve the analysis strengths, weaknesses, opportunities and threats resulting in two assistive device designs (Robins et al., 2010).

In this research, the focus is on patients as decision makers to explore how well the CWA approach can accommodate the lay person. CWA helps even non experts with a comprehensive and systematic representation of the system, for identifying potential problems, understand how systems interact with other agents and the information flow, and identify the means-end relations to examine the path between individual element and system goals.

#### **4.6.3 CWA Phases for Decision Support**

CWA consists of five phases (Vicente 1999; Naikar et al 2006; Bisantz and Burns 2008; O'Connor 1997). The order in which the phases are performed is largely up to the analyst and influenced by access to information but tends to work from the outside in, i.e., from



organisational considerations to individual skill profiles. The five phases of CWA are as follows:

- In this thesis, the first phase is Work Domain Analysis (WDA). WDA is concerned with mapping the purposive and physical 'big picture' of the work domain, typically in the form of an Abstraction Hierarchy.
- The second phase, is Social Organization and Cooperation Analysis (SOCA), which concerns the division of functions between elements of the socio-technical system.
- The third phase is Control Task Analysis which establishes what needs to be done for the system to fulfil its purpose, exemplifying possible pathways between input states and output decisions. It is a mapping of information processing structures that the system as a whole need to navigate. This stage of CWA is typically performed using Rasmussen's Decision Ladder (Rasmussen et al, 1994).
- The fourth phase, Strategies Analysis, concerns the routines that could be used to carry out the activities identified in Control Task Analysis.
- The fifth phase, Skills and Worker Competency Analysis, concerns the mapping between the required competencies of workers and the system constraints, and is typically performed using the SRK taxonomy (Skill-based, rule-based or knowledge-based (Rasmussen et al., 1994; Vincente 1999)).

#### **4.6.4 Drawback of CWA**

Although CWA has been used for more than 20 years, it is not widely used or applied, hence there is a lack of people specialising in CWA. An assumption in this thesis is that CWA is carried out with CWA personnel who are educated and trained in the field CWA. CWA analysis might be time consuming and challenging to involve stakeholders.

## **4.7 UML for Translating CWA to Software Specification**

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Application of human factors for systems engineering and software design necessitates the need for translating human elements quantitatively throughout design, development and testing (Booher 2003). This necessitates the need for software approaches for capturing and translating CWA analysis into software specifications.

### **4.7.1 Why UML?**

UML was chosen due to the following reasons: UML is a standard modelling language in software engineering for specifying, visualizing, constructing, and documenting the artefacts of software systems (Guiochet et al., 2003; Pilemalm et al., 2007; Gherbi and Khendek 2006; Hai et al., 2005; Wiering et al., 2004; Alavizaedh 2007). Moreover, UML is aimed at object-oriented design to describe the structural and behavioural properties of the software being created.

### **4.7.2 Application of UML**

At the beginning of this research UML was chosen but due to the complexity in analysing decision making to support both novice and experienced patients as well as to understand the application of skills, knowledge and rule-based decision making, CWA was chosen. As UML is popular in the design of software, it was found useful in the translation of CWA analysis to UML for the software design and implementation. UML was used for many reasons.

UML describes the structure of data, actions and processes and aids in the translation of design into software (Pilemalm et al, 2007; Berkenkötter 2003). UML is a notation for describing different views of a system using structural diagrams (to capture the physical

organisation of things in system and how the objects relate to one another) and behavioural diagrams (to capture a particular facet of a system in terms of the behaviour of the elements in the system) (Rumbaugh, Jacobson, & Booch, 2004; Pitone and Pitman 2005). UML presumes an object-orientated design approach using use case diagrams, class diagrams, sequence/collaboration diagrams, activity diagrams, and statechart diagrams. Each kind of UML diagram provides a different perspective of the system to be developed. For instance: use case diagrams are suitable for requirement capture to show the relationships between actors (stakeholders) and use cases in the systems; Class diagram shows the classes and their relationships; state diagrams describe system states and transitions to be triggered for state changes; and sequence diagrams displays object interactions arranged in a time sequence. UML is supported by freely available tools and textbooks (Bertolino and Mirandola 2004; Dennise et al, 2009). UML has been effectively used in the medical domain (Guiochet et al., 2003; Juan and Chen 2005; Lee 2007); decision support (Frize et al., 2005; Porres et al., 2008; Vasilakos 2012) and in complex systems (Vasilakos 2012; Huggins and Ressler, Selic 1998; Bruegge and Dutoit 1999).

*Table 4.2: UML Diagrams*

Diagram Type	Description
Use Case	Use case diagrams represent the interactions between the system and the users or other external systems. Useful for mapping the functional requirements or user needs for the system.
Class	Uses classes, types and interfaces and their static relationships.
Package	Involves with grouping of classes and interfaces.
Sequence	Sequence is an interaction diagram that specifies the type and order of messages passed between elements during execution.
Activity	Captures the sequential and parallel flow from one activity or behaviour to the next activity similar to flow charts.
Component	To represent the organisation and dependencies involved in the implementation of a system.
Deployment	Shows how components are configured at runtime.

This research does not make a claim that UML is the only approach that can be used, but it was selected for being representative of the discipline of software design and development which is familiar to IT professionals.

#### **4.7.3 UML Models**

UML modelling includes various diagrams (Pilone and Pitman, 2005) to capture a particular facet of a system including: structural diagrams and behavioural diagrams. The structural diagrams capture the physical organisation of things in system and how the objects relate to one another. Behavioural diagrams focus on the behaviour of the elements in the system including operations and interactions. Some of the commonly used UML diagrams are represented in Table 4.2.

#### **4.7.4 Drawbacks in UML Integration**

UML modelling helps in understanding the knowledge required for decision support system, but they have limitations for medical problem solving especially in unanticipated and ill-structured situations (Hajdukiewicz et al 2001). An assumption in this thesis is that software engineers are educated and trained in computer design and programming especially in the application of UML. Sometimes, if the translation of CWA to UML is not taken systematically as described in Chapter 8 then designers might design UML based on assumptions hence losing the human elements or modelling analysis in the design as found in the literature.

## **4.8 Testing**

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While the aim of the thesis was not to produce a finished product, the culmination of the design process was a set of prototype designs. These were evaluated in terms of a user interface concept (chapter 9) and a paper-prototype (chapter 10). As longitudinal study was not possible in this thesis, the CISDA process and the decision support were evaluated through various means including CWA verification, case scenario testing, assessment with doctors, patient verification, assessing patient decisions with the doctors and testing with experts including IT professionals and psychologists to gather their implications on using CISDA using a questionnaire feedback study.

### **4.8.1 CWA Testing**

CWA testing was carried out using patient's decision making case scenarios collected in this thesis from the patient and the literature as shown in Chapter 10.

### **4.8.2 Case Scenario Testing**

Patient decision case scenarios have been used to test the app as shown in Chapter 10. Each case scenarios were taken and the support provided by the mobile prototype were analysed to validate the process.

### **4.8.3 Pre and Post Test**

One of the methods used in evaluation study (Chapter 10) is pre and post-test evaluation. This evaluation has been used, for e.g., Clifford and Murray (2001) for pre and post-test evaluation of a project to facilitate research in a hospital setting; pre and post-test is used to understand the effects of training on internet self-efficacy and computer user attitudes (Torkzadeh and Van Dyke 2002) and; Wallace et al., (2009) used pre and post-test to evaluate

the efficacy of rendering patients with literacy-appropriate education guide with brief counselling.

In this thesis pre and post-test is used to identify, the change in decision making by patients. The pre and post-test were conducted first with a questionnaire in pre-test which included a hypothetical patient (name Ann) problem and the decisions the patient could make for better self-management. Next participants were shown the paper prototype and a video of how patient Ann records her everyday activities (diet, medication and exercise) and gains knowledge and decision support using the prototype developed in this thesis. Finally, a post-test survey is conducted by giving out the same hypothetical Ann's problem as in the pre-test. Participant's feedback on decision making for Ann is recorded before and after presenting the prototype to see if there has been any change in decision making. As there could be some bias in this form of evaluation due to the way information is presented, the test was followed by collective qualitative feedback or comments from the participants along with a questionnaire study to understand the perceived usefulness of the prototype.

#### **4.8.4 Expert-based Testing**

This testing involved expert feedback, like doctors, IT professionals and psychologists to gather feedback. The prototype was tested with doctors to: (i) verify the prototype for supporting self-care decision making with the doctors involved in the study; (ii) validate the decision made by patients using pre and post-test scenarios and prototype with the doctors not involved in the study; and (iii) to gather doctor's perception on the self-care decision aid prototype developed.

#### **4.8.5 Data Analysis**

As user testing feedback were collected using questionnaires, the data were analysed similar to the questionnaire study analysis in section 4.4.5 using descriptive methods.

## **4.9 Ethics and Working with Human Subjects**

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At the beginning of the research, Glenfield Heart Research group, a leading cardiac care centre in the UK was consulted about the study and access to patients was explored. Two ways of approaches were found to get access to patients: (i) CVD patients could be contacted at the hospital by obtaining ethics approval from the Ethics committee at the hospital and (ii) CVD patients could be contacted through British Heart Foundation using University level ethics approval. The study wanted to explore cardiac patients at various duration from diagnosis (0 years to 20 or more years with CVD) from different cities. Moreover, hospital patients usually have acute conditions and non-hospital patients have more chronic condition, hence university level ethics was found to be appropriate and useful for this research.

### **4.9.1 Ethical Approval**

Projects involving human participants require approval from the University of Birmingham School Ethics committee. Approval for this PhD research was covered by the ethical approval for research under the BRAVEHEALTH EU project (which supported part of the research). This required informed consent to be obtained from participants and for any data collected from them to be rendered anonymous and securely stored.

### **4.9.2 Identifying Potential Participants**

Patient participants (diagnosed with CVD) were recruited by contacting heart support groups in the UK Midlands. Initial contact with the support group coordinator was made in person, by email or by phone. Research presentation and information leaflets were given to participants. Participants who were interested in this study were asked to contact their group coordinator and give their names. Following this recruitment process the studies were conducted.

Doctor recruitment was carried out in several ways. First the cardiologists at Glenfield hospital in Leicester, UK were contacted by email providing details of the study. Due to low response, the GPs on local health services in Leicester were contacted. One GP (a friend) showed interest in the study. Email was sent to the GP requesting participation for the study. GP forwarded this email to other GPs in the nearby practice and friends.

IT and Psychology Experts at the University of Cambridge were contacted by email specifying the date of presentation using university research support. IT Experts at research labs were contacted by email explaining the research and its implication in various research labs like HP, Microsoft, IBM and Qualcomm. Also presentation was given at IEOM 2015 Conference at Dubai to gather feedback from participants around the world.

#### **4.9.3 Care and handling research participants**

Participants were informed that they can withdraw from the study whenever they wish or can request to have any data generated from their responses withdrawn from subsequent analysis. As the study involved the collection of material through questionnaires and focus groups, it was felt to gather participant level of ethical approval as well. Patient studies were conducted in a place and time convenient for the participants.

#### **4.10 Sample Size**

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The survey of patients was conducted to understand patients' opinion, so the numbers were considered as less important than the opinions collected. As the approach involves case studies, the aim is to collect as many cases as possible to get a broader range of data



regardless of consensus so as to generate as many unique cases as possible. The following assumptions are used in this thesis for sample size representativeness:

- In terms of qualitative analysis smaller sizes are acceptable. Wiklund (2011) specifies that sample size between 5 and 15 are recommended for medical devices.
- Studies can be conducted with 30 or more participants not because this sample size would give any ‘strength’ or ‘power’ to the analysis but because this would give a broad enough range of case studies which would be shared by different people. The focus in this thesis was really on getting a good sense of ‘typical’ experience rather than an exhaustive catalogue of all experiences.

During the study for exploring research questions 1 and 2, the following rules determined the sample size:

- Focus group: The focus group studies were conducted till a threshold was reached, i.e., till no newer information were collected.
- Interviews: For studies involving patients, mixed group of participants involving different age groups and CVD diagnosis duration for generalising and representativeness of the population.
- Survey: Patients consisting of mixed age groups and CVD diagnosis duration were contacted for obtaining adequate information required for the study.

As doctors were involved for understanding decision making process and for evaluating concept, the studies were conducted till a threshold was reached.

## **4.11 Summary**

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This chapter provides an overview of the research methods used to achieve the thesis aim. These methods and process helps to gain a deeper view of the needs for supporting self-management using CISDA framework in the following chapters.

## Chapter 5 NEEDS ASSESSMENT

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*"Physicians can learn to be experts in diabetes management, but only patients can be experts in the conduct of their own lives." Anderson (1995; pg 413)*

Needs assessment is the first phase in CISDA process. This phase explores self-management needs, day-to-day experiences and decision making using literature, focus groups and questionnaires. This chapter starts with guidelines for the developers to help in the implementation process followed by a case study for this phase. The aim of this phase is to not only gain insight into the experience and knowledge of elderly CVD patients' but also to demonstrate how to gather software requirements for supporting everyday self-management. This chapter also shows the treatment adherence (like diet, medication, exercise) and decision making are inter-related rather than an episodic event.

### 5.1 Needs Assessment Phase Guidelines

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This section provides guidelines for decision aid designers to carry out the needs assessment phase derived from the CISDA process. This phase and the next phase addresses the research question 1: "How to describe everyday decision making for software design and development?" This question is explored by looking at "How do patients actually self-manage in day-to-day life?" "What decisions do they make in day-to-day self-care?"

#### **Purpose**

This phase covers self-management with regards to treatment adherence (diet, medication and exercise). DA designers can explore the following in this phase:

- Gather information on day-to-day self-management experiences.
- Problems faced by patients in day-to-day self-management with regards to diet, medication and exercise.
- Self-care decisions faced by patients in everyday life.
- Requirements for self-care management

## **Thesis Composition**

This phases consists of:

- Background Study – to gain an understanding for self-management by exploring the existing support.
- Understanding Patient Experiences (Study I) - to gain insight into elderly CVD patients' and caregivers' experiences and issues in every day self- management.
- Patients Medication Knowledge Survey (Study II) - to find out in detail how much information patients knew about a medicine like Warfarin or Statin.
- Software Requirements – requirements were extracted based on the above studies.
- Phase Summary – provides summary of the phase.

## **Methods**

This phase uses:

- Literature search using thematic analysis
- Focus Groups (section 4.2.1) using thematic analysis
- Questionnaire (section 4.2.3) using quantitative analysis

The primary aim of Needs Assessment is to gain insight and understanding into the challenges faced by patients in their day-to-day decision making. In addition to the review of literature, focus group interviews and questionnaires, further information could be

gathered through observation (Sekaran 2003) and ethnography (Helander 2014) to gain detailed insight into specific instances.

### **Participants**

Patients diagnosed with CVD from BHF and local heart support groups.

### **Outcomes**

Requirements for self-care management derived based on the understanding of day-to-day self-management experiences and decision needs studies with CVD patients.

### **Quality Criteria**

1. Does this phase provide a complete set of requirements for self-management?
2. Do the studies provide consistent data for understanding self-management?
3. Do the studies provide insight into the decision making needs?

### **External Dependencies**

Patient participants to review the details captured in the study.

## **5.2 Background Study**

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This section tries to get an overview of the kind of support available and the need for self-management. Moser et al. (2012) and Lainscak et al. (2011) indicate that CVD can be controlled through modifiable behaviours and intermediate biological risk conditions involving:

- Increasing physical activity, regular medication and healthy diet;

- Reducing smoking and alcohol; and
- Better symptoms recognition.

Based on the above risk conditions, some of the studies which provide study outcomes for successful CVD self-management are shown in Table 5.1 to provide some insight into self-management.

*Table 5.1: Published Research on Self-Management*

<b>Paper</b>	<b>Diet</b>	<b>Exercise</b>	<b>Medication</b>	<b>Diary</b>	<b>Alcohol</b>	<b>Study Outcome</b>
Walters et al. (2010)		X		X		The main outcome measure is adherence to physical exercise guidelines.
Pfäeffli et al. (2012)		X				This exercise program was an effective way to deliver exercise-based rehabilitation.
Varnfield et al. (2011)	X	X		X	X	Preliminary results show high usage rates and acceptance by participants.
Qudah et al. (2010)			X			Helps in checking ECG rate and to manage complex medications.
Zao et al. (2008)	X	X	X			Shows that elders were satisfied by the Health Pal and a desire to own it was excited.

Table 5.1 shows support for one or more of the biological risk factors and the positive outcomes achieved. For effective self-management the system should provide support for diet, exercise, medication, alcohol consumption and help maintain a diary for managing health. For example, record exercise and diet intake (Varnfield et al., 2011).

### 5.3 Understanding Patient Experiences (Study I)

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The purpose of this study is to gain insight into elderly CVD patients' and caregivers' experiences and issues in self- management.

### 5.3.1 Methods and Participants

This study uses focus groups. The participants demographic is shown in Table 5.2.

*Table 5.2: Demographics of Participants*

	Number of Participants
Gender	
Male	22
Female	12
Age	
50-59	5
60-69	18
70-79	10
80-89	1
Education	
Graduate Education	5
College	8
Secondary School	7
Did not Graduate from High School	14
Employment	
Employed	5
Not Employed	15
Retired	14
History of heart condition:	
Less than 6 months	4
6-1 years	2
2-3 years	2
4-5 years	8
5-10 years	11
10+ years	7
Have you gathered information from friends and family?	14 (yes) 20(no)
Do you have a family history of cardiac problems?	7 (yes) 21(no) 6(not sure)

### 5.3.2 Data Collection

Semi-structured discussions were conducted with the participants. With participant's permission, all discussions were audio recorded and notes were taken. Participants were asked to describe their day-to-day self-management experiences and issues in exercise, diet, medication and decision-making using the question prompts in Table 5.3.

*Table 5.3: Questions for Discussion*

<b>Topic</b>	<b>Question</b>
<b>Diet</b>	Tell us about your diet? What food do you need to avoid? Does your medication have any effect on your diet? What sort of decisions do you need to make?
<b>Medication</b>	Tell us about your medication? What problems do you have? What sort of decisions do you need to make?
<b>Exercise</b>	Tell us about your exercise? Do you know your limitations?

The above questions were refined after the first focus group session. For example, in the first focus group questions such as “Tell us how you make decisions?” were asked. This caused confusion with the patients and one of the participant said – “We don’t make any decisions, our doctors make it”. Patients were not really aware of the decisions they were making so direct questions on decision making were avoided.

### **5.3.3 Analyses**

Analyses were carried out in two stages. First, analysis was carried out to get information based on the notes during discussion to gain an overview. The summary of the findings was sent to the support group convener to offer an opportunity for participants to comment on them. Second, analysis was carried out by transcribing the focus group discussions for further understanding on self-management following the approach of content analysis (Bainbridge and Sanderson 1995).

Each transcript was divided into units which encompassed a single proposition (i.e., a single, complete idea). For example, the following extract can be decomposed into three propositions: “...it’s also knowing what you can’t eat with things like Warfarin because there are certain things that will contradict, like cranberries, broccoli and there’s grapefruit juice with Statins” (Female). Proposition 1: Cranberries cannot be eaten when taking Warfarin;



proposition 2: Broccoli cannot be eaten when taking Warfarin; proposition 3: Grapefruit juice cannot be drunk when taking Statins. Another proposition is ‘It is important to know what you can’t eat when taking Warfarin’ – which is a meta-proposition containing the other three prepositions. It is worth noting that the transcriptions represent the views of the focus group participants and no claim is made as to the medical validity of these views for this analysis. The following sections present the findings in detail.

### **5.3.4 Results**

The results are summarized based on appropriate quotes that best illustrate each concept, and within each section, patterns revealed by the data are discussed in terms of self-management requirements and decision making. The transcriptions were grouped under following sections based on the compliance needs for self-management such as: diet, medication and exercise.

Although the focus group participants raised a lot of concerns on diet, medication and exercise throughout the study another self-management aspect that was reflected was that:

*‘Self-management depends on how well patients sleep and feel on the day.’*

#### ***Diet***

As CVD patients have various dietary regulations (together with other health problems that would influence their diet), the participants’ experiences of diet were captured. This study has helped to understand ‘what patients require for managing diet?’ as shown in Table 5.4. It was noteworthy that the question about drug / food interactions was most likely to spark the liveliest debate in the focus groups, which highlighted the contradictory knowledge and level of concern this raised. Table 5.4 shows that patients seem to face decisions such as: what you can eat. Problems seem to be ill-structured or not well defined; involving uncertainty; for managing and understanding their health.

Table 5.4: What Patients Require for Managing Diet?

Diet Requirements	Study Evidence	Findings
Side Effects/ Drug Interactions	<p>“The IRN levels are pretty dependent on what you eat.” (Female)</p> <p>“...it’s also knowing what you can’t eat with things like Warfarin because there are certain things that will contradict.” (Female)</p> <p>“If you are on Statins as well making sure that you obviously need to have food that are not going to increase your cholesterol.” (Female)</p> <p>“With Statins you are not suppose to have grapefruit.” (Female)</p>	<p>Participants do not seem to be well informed or have a good understanding about drug interactions with foods or they were not sure whether these interactions were affected by dosage.</p>
Diet Regime (including amount)	<p>“I usually have a small supper; I have 4 small meals in relation to what I use to eat.” (Male)</p> <p>“Try and make sure you have some sort of diet each day if you can.” (Female)</p> <p>“more or less eat a wonderful healthy diet but keep it same each week so you don’t have great peaks sometimes.” (Male)</p>	<p>Few of the focus group participants thought that following a regular diet regime on a weekly basis might help to avoid serious adverse effects.</p>
Alcohol	<p>“I think alcohol is one of the main thing that you need to be monitoring as it can alter your blood.” (Female)</p> <p>“Alcohol intake.” (Male)</p>	<p>Alcohol affected their health and well being as shown in Figure 2.1 (Chapter 2)</p>
Diet Advice	<p>“It’s just making sure that you eat a healthy diet really. We don’t watch anything particular do we?” (Male)</p> <p>“We don’t eat too much fat like butter. Always look for low fat, no or low salts.” (Female)</p> <p>“If you want a burger you can’t have every night or every week. Turkey or fried chicken you can have once a month.” (Male)</p>	<p>Information given to the participants does not appear to be uniform and standardised.</p> <p>There were lot of arguments on what to eat, what not to eat, how much to eat, and what is good for them. This makes them more diet conscious in terms of both quantity and quality.</p> <p>Patients seem to get most of their diet information from doctors, nutritionists, nurse, and leaflets, but were also likely to gain information from other patients (who might be taking different drugs or dosages for different symptoms).</p>
Reminder	<p>“What to eat on a daily basis?” (Male)</p> <p>“I think it would be good if there was a constant reminder of dietary requirements.” (Male)</p>	<p>Felt reminders can help them to follow their doctors’ diet advice and intake as identified in Figure 2.1 (Reminders; Chapter 2)</p>
Decision Making	<p>“What you can eat? It’s quite difficult.” (Female)</p> <p>“It is a very difficult decision to make. I try to avoid red meat, salt, dairy, butter...” (Male)</p> <p>“there is a big decision making on dietary.” (Male)</p> <p>“you rely on the carers...you do have to make conscious decisions on what you eat because most of us can’t exercise.” (Male)</p>	<p>Decision making in day-to-day life does not involve any acute or episodic events as represented by DAs in Chapter 2. The decisions seem to be somewhat similar to the decisions highlighted by Entwistle et al. 2004 in Chapter 2.</p>

Table 5.5: What Patients Require for Managing Medication?

Medication Requirements	Study Evidence	Findings
Reminders/ Time	<p>"I take so many tablets at different times, so that's quite complicated." (Male)</p> <p>"I am a diabetic and take lot of tablets" (Male)</p> <p>"I think the timing is most important because you need to take tablets same time each day." (Male)</p>	<p>Patients forget and miss the dosage.</p> <p>Some of them overcome this problem by combining medicine intake with meal times.</p>
Prescription (includes dosage)	<p>"You got to remember and you got to participate in it and yeah medication is a problem." (Male)</p> <p>"I went 3 days without medication just to see and I was so ill and ended up in hospital and never did that again." (Male)</p>	<p>A common feature of the participants in these focus groups was the co-occurrence of CVD with diabetes, so participants were not sure about their amount of Insulin intake before a party as mentioned by a patient.</p>
Side-Effects/ Advice	<p>"There is a question of conflicting advice." (Male)</p> <p>"It will be good if we can have a guide to medication like an idiot's guide" (Male)</p>	<p>Participants either had too much information available or they did not have much information on side-effects or interactions with food substances or other medications.</p>
Decision Making	<p>"I suppose you got to say now do I have this amount of insulin which is normal or do I give myself more so I can enjoy some of the food..." (Male)"</p> <p>"I forget to take that beta blocker in the morning and it's now 4 o'clock in the afternoon do I take it then or do I drop that one altogether because I got another one at 6 o'clock. (Male)"</p> <p>"I look at the boxes, at breakfast in the morning and I think I forgot to take my tablets last night" (Male)</p>	<p>Participants seem to miss the medication frequently which involves decision making as to whether to skip the dose altogether or to go for a delayed intake. This decision problem is discussed in Chapter 7.</p>

## ***Medication***

Due to the nature of the disease and the age of the population in the study, most of the focus group participants' take more than one medication and at different times of the day. During discussion with patients, it is apparent that often patients rely on the colour and shape of medication which is worrying as discussed by the patients:

Person 1: "I know my tablets based on the colour and the size, I take the white one in the afternoon...." while another person interrupted as;

Person 2: "Yes, that's true..."

Person 3: "But, did you see that they have changed that medicine now? The other day I went to the chemist and she gave me the medicine, I said this is not the medicine I want, it looks different but she said no it is the same one, they have changed the shape!"

Person 2: "Yes, I had the same problem". The focus group data relating to medication were grouped into subsections as shown in Table 5.5 "medication requirements" using illustrative quotes from participants in "study evidence". Table 5.5 also shows the key findings from this study for supporting patients in everyday medication management.

In terms of taking medicines, most of the participants felt that they frequently miss the medicines as mentioned in User Experience study. One participant mentioned that:

"I need reminding to take tablets as I forget very easily." (Male) Most of the participants agreed, while another felt

"Initially it is a problem, but then you get used to it." (Female)

This study shows why there is lot of readmissions on medication adherence (Chapter 1). Although the time of consumption is well documented, patients still forget due to lack of

systematic approaches. The decisions patients seem to make in everyday self-management as presented in Table 5.5 seem to be:

- Related to medication compliance (e.g. what to do on miss dosage?).
- Unique.
- Involves uncertainty as mentioned in section 1.2 (complexities).

### ***Exercise***

This section deals with patient exercise which also plays a major role in health and wellness. As the participants are from an active Heart Support Group they have been provided with a structured exercise program with an instructor, hence they seem to be well informed about the exercises they need to do, their limitations, and pace except for few concerns (Table 5.6).

*Table 5.6: What Patients Require for Managing Exercise?*

Exercise Requirements	Study Evidence	Findings
Advice	<p>“Some of them feel afraid to do their exercise, again because they are frightened that they are going to have another heart problem or something.” (Female)</p> <p>“Well the more aerobic exercise you can do, the better.” (Female)</p> <p>“It’s alright to get out of breath it’s working within your own body levels really but working your heart.” (Male)</p>	General advice on the need for exercise, what exercises to do and limitations?
Reminders	<p>“The new lady is a bit scared in the exercise.” (Female)</p> <p>“Everyone need to know his or her limitations.” (Female)</p> <p>“There’s no disgrace, stop it if you can’t do it.” (Female)</p> <p>“Set a target and keep within a range.” (Male)</p>	Reminders for staying active and for encouraging them to do exercise.
Decision Making	<p>“When to stop?” (Female)</p> <p>“A bit unsure (to do exercise).” (Male)</p>	Exercise management does involve some level of making the right decisions about doing exercise and limitations.

The focus group data relating to exercise were grouped into subsections as shown in Table 5.6 “exercise requirements” using illustrative quotes from participants in “study evidence”. Table 5.6 also shows the key findings from this study for supporting patients in everyday

medication management. This study shows that patients need general advice for exercise and that recently diagnosed patients (less than 1 year) with heart disease expressed worry and were unsure whether their heart would cope with exercise, but the general impression was that exercise should be undertaken at one's own pace and at comfortable level.

### **5.3.5 Summary**

Tables 5.4 - 5.6 indicates that the focus group participants face a wide range of self-management and decision making needs that could have consequences for their health. In general decision making necessitates a lot of planning for their daily routine (e.g., in terms of making sure that they take medication with them when they go out, in terms of deciding when to book a table if they are eating out, in terms of deciding how long it would take to walk to the shops and back).

During the focus groups discussion, it was felt that participants face much confusion about their medications including: time of consumption, interactions with food and other side effects as mentioned in Table 5.6 and 5.8. A further question, therefore is to consider, "how much information patients have on their medication needs?" and "where do patients get healthcare information?" In the next part of this chapter, further insight into patients' knowledge and information sources will be gained through a questionnaire survey.

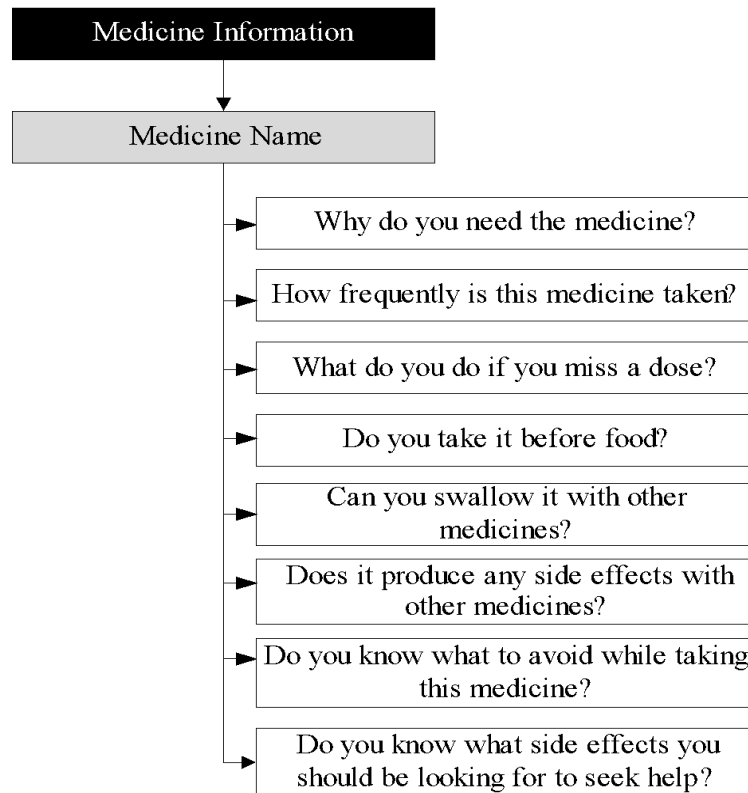
## **5.4 Patients Medication Knowledge Survey (Study II)**

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As the previous study showed a lack of knowledge about patients' medication, this section is used to find out in detail how much information patients knew about a medicine like Warfarin or Statin.

### 5.4.1 Method and Participants

This questionnaire study was conducted with 25 CVD patients from the British Heart Foundation in Cheshire and Royal Alexander hospital.



*Figure 5.1: Medication Information Questionnaire*

### 5.4.2 Data Collection

The questionnaire (Appendix D, Figure 5.1) for this study was developed based on the Ontario's Framework (2007) medication guidelines for patients as well as on the concerns from the previous studies (Study I and II) to explore further. Participants were asked to choose one medication and give details for the medication.

The suggested list of medicine included: simvastatin, statins, aspirin, and warfarin which were commonly mentioned by patients in Study I. By allowing the participant to choose the medicine it would be useful for comparison and to understand their knowledge. The questionnaires were tested for readability and comprehension by showing them to conveners

of the heart support groups. Any misunderstandings or ambiguities were corrected prior to submitting them to the respondents.

### **5.4.3 Analysis**

As interpretation of patient responses to medication management involves some medical expertise patient responses were analysed with the help of a physician from a local hospital (who agreed to review the results and provide feedback on the study). As mentioned above, after a brief discussion about the various medications they take, the need for being informed and transcripts from the preliminary study, participants had started by writing down their responses to the questions. The responses were grouped under broad headings as shown below.

- **Medicine Requirement:** participants were asked to select a medicine they were prescribed and its effects
- **Time:** deals with the frequency of medication intake, missing medication and how medicine should be consumed.
- **Side Effects:** includes all the questions related to side effects or counter effects of the medication.
- **Information Source**

### **5.4.4 Results**

On discussion with the physician it is apparent that, in general, patients seem to have basic knowledge of their medication (however participants were not asked to provide details of the dosage and this could be a reason why there is variation in the frequency of the medications). The questionnaire findings are as follows.



### ***Medicine Requirement***

11/25 participants selected Statin group of medicine, 7/25 participants selected Aspirin, 2/25 participants mentioned candasartan, another 2/25 participants mentioned clopidogrel and the rest mentioned amaroidia<sup>1</sup>, biosprolol and warfarin.

Some participants mentioned in the questionnaire that Statins lower cholesterol while others indicated that they prevent heart problems and a few metioned that by lowering the cholesterol level it would help the heart. On discussing these variations with a physician it was found that statins are prescribed for lowering cholesterol levels to prevent heart disease. This shows that patients seem to have a rough idea (but not always complete or accurate idea) about the need for medication. Table 5.7 gives the response of the participants for medicine requirement. Patients seem to have some idea of their chosen medication. But as patients can have multiple medications it is essential to provide them the need for medication.

*Table 5.7: Medicine Requirement (number of participants' response shown in brackets)*

<b>Medicine</b>	<b>Requirement</b>
<b>Statin</b>	Help to control Cholesterol and Help Heart (1 participant) Heart Disease and Protection of Stents (2 participants) Blood Pressure (1 participant) Lower Cholesterol (3 participant) Heart Problems (1 participant) Prevention of Arterial Heart (1 participant) Prevent Stroke (1 participant) Not sure (1 participant)
<b>Aspirin</b>	Blood Thin (6 participants) Heart Problems (1 participant)
<b>Candesartan</b>	Blood Pressure (2 participants)
<b>Clopidogrel</b>	Heart Problems (1 participant) Blood Thin (1 participant)
<b>Amiodarone</b>	Heart Rhythm (1 participant)
<b>Bisoprolol</b>	Heart Regulation (1 participant)
<b>Warfarin</b>	Blood Thin (1 participant)

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<sup>1</sup>amaroidia, is the name mentioned by the participant but the physician suggests it could be amiodarone

## Time

Participants' response to medicine time (i.e., time for taking medication) is shown in Table 5.8. This study reinforces Study I and II findings on supporting medication management using time or reminders.

*Table 5.8: Medicine Time (number of participants' response shown in brackets)*

	Once every day (6)  No response(1)	Nothing No problem, take next day Never missed - would wait till next day Just take one the following day Take next day (3) Leave it until the following day No response(2)	Yes(2) Not sure(1) No response (1)      Not sure (1) No(3) Yes(2) No response(1)	No response(1)
<b>Aspirin</b>	Once every day (6 participants)  Twice every day (1 participant)	Take next day (3) Do Nothing (2) No response(2)	Not sure (1) No(3) Yes(2) No response(1)	Yes (5) No (1) No response(1)
<b>Candesartan</b>	Once every day(1)	Take next day(1) No response(1)	Yes(1) No(1)	Yes(1) No(1)
<b>Clopidogrel</b>	Once every day(2)	Take next day(2)	No(2)	Yes(1) No(1)
<b>Amiodarone</b>	Once every day(1)	Take as soon as I remember	Yes	Yes
<b>Bisoprolol</b>	Once every day(1)	Next day(1)	Yes(1)	Yes(1)
<b>Warfarin</b>	Once every day(1)	Arrange INR blood test(1)	No(1)	No response(1)

## Side Effects

Participants' response to side effects is shown in Table 5.9. Basically all drugs would have some side effects but the frequency of its occurrence may be rare to occasional. However, patients should be aware of some common side effects for example aspirin causing heart burn. So, it is essential that patients are informed about the common side effects, but because patients take more than one medication, patients might remember relatively little of what a doctor may have told them during a consultation, and are reluctant to ask for more information, either through a fear of appearing foolish or being conscious that the doctor is pressed for time and remember relatively little of what doctor has told patient (Swan and

Borshoff 1994, Cassileth et al 1980, Muss et al 1979). One of the participants mentioned that:

“I take 12 medicines every day; hence it is difficult to spot side effects.” (Male) This reflects the findings in Study II.

*Table 5.9: Medicine Side Effects (number of participants' response shown in brackets)*

<b>Tablet</b>	<b>Interaction with other medicines</b>	<b>Foods to avoid</b>	<b>Side effects</b>
<b>Statin</b>	No(7)	Grape Fruit(5)	Muscle Aches(2)
	Yes(1)	Cranberry and Alcohol(1)	Numerous according to information sheet given with medicine(3)
	Not sure(2)	Grape Fruit and Alcohol(1)	Any significant effects(1)
	No response(1)	Cranberry, Grape Fruit and Alcohol(1)	Dizziness and weakness(1)
		Alcohol and herbal remedies(1)	Don't know(2)
		Not sure(1)	Can't remember(1)
		No response(1)	No response(1)
<b>Aspirin</b>	Not sure(3)	Grape Fruit(2)	Don't Know(2)
	Yes(2)	Alcohol (3)	Numerous according to information sheet given with medicine(1)
	No(1)	Grape Fruit, Alcohol(1)	No response(2)
	No response(1)	Not sure(1)	Yes I know the side effects(1) No response(1)
<b>Candesartan</b>	No(1)	No response(2)	No response(1)
	No response(1)		Yes I know the side effects(1)
<b>Clopidogrel</b>	No(2)	Alcohol(1)	Don't know(1)
		Nothing(1)	No response(1)
<b>Amiodarone</b>	No(1)	No response(1)	Skin inflammation in sun
<b>Bisoprolol</b>	Yes(1)	Nothing (1)	Numerous according to information sheet given with medicine (1).
<b>Warfarin</b>	No(1)	Cranberry, grape fruit, herbal remedies, aspirin(1)	Yes I know the side effects(1)

This section shows that patients' decision making also involves identifying the side effects which is not easy for them with so many medications.

#### **5.4.5 Summary**

Study III shows that focus group participants rely heavily on doctors and hospitals. This may be because patients do not want to go through too much information or due to lack of confidence or it might be that the content may not be targeted to patients' real needs. Moreover, patients are not alone in managing their health condition; they depend on caregivers, doctors and family members. This sheds light on why the current DAs are not widely adopted as they only focus on information provision rather than supporting everyday decision making like identifying medication side-effects or doing exercise.

### **5.5 Software Requirements Specification (Iteration 1)**

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The background section (5.2) and the studies (I and II) in this phase helps to understand the need for supporting diet, exercise and medication. Tables 5.4 -5.6 show the requirements needed for supporting self-management. Tables 5.7, 5.8, and 5.9 helps to further explore the needs of the patients with regards to information on the medicine, timing, and side-effects. Table 5.8 shows that self-management is not a single entity. For example, diet is dependent on medication, knowing the side-effects and interactions with various medications. Hence for effective self-management there is a need to address all the treatment adherence like diet, medication and exercise. Using these studies, the specification for software requirements is documented here using the IEEE Software Specifications Template (ANSI/IEEE Std. 830-1984).

Table 5.10a Software Requirements Specification - Introduction

<b>Software Requirements Specification – Introduction</b> This table provides introduction to the self-care decision support mobile app developed as a case study in this thesis for supporting everyday decision making.	
Purpose	The purpose of this table is to highlight the requirements for the ‘Self-care Decision Support System’ mobile prototype. This document is intended as a reference for developing the system as well as in client communication.
Product Scope	The ‘Self-care Decision Support System’ is a smartphone-based application which supports CVD patients in everyday self-care management and decision making. This research is not focused in the end product but in the process hence the implementation of mobile application is not dealt in great detail. Patients diagnosed with CVD can record their diet and medication timings, side-effects/ allergies and advice from doctors or nutritionists. The system will remind users for treatment adherence. The mobile phone needs to have access to internet to fetch and display evidence-based information for patient’s self-management. The application also has the capability to display the side-effects/ allergies and advice as needed for the patient.
Users	Older adults diagnosed with CVD.
Stakeholders	Doctors, nurses, caregivers concerned with patient’s self-management.
Mobile App	<p>Prototype is developed for mobile phones. Smartphone delivery method is chosen based on the studies in this section. Patients need to have:</p> <ul style="list-style-type: none"> <li>Access to diet advice and regime whether at home or in the restaurant</li> <li>Patient need reminders for taking their medication</li> <li>Access to exercise advice at home or outside in exercise classes</li> </ul> <p>Moreover, literature studies including Table 2.1 and 2.4 show that most of the decision support selected in the studies used web and/or mobile delivery. With the increasing number of mobile applications in the market, mobile phone would be the future and it imposes greater challenges on the health care system. Moreover, mobile application can be useful:</p> <ul style="list-style-type: none"> <li>Record, track and remind patients for treatment adherence anytime, anywhere.</li> <li>Mobile phones have various sensors like pedometer which can be used to automatically record patient activities with minimal interference.</li> <li>As there is a need for patients to record their diet intake, it would be easier to take a photo or video of their diet for easy recall.</li> </ul>
Reference	IEEE Software Engineering Standards Committee, “IEEE Std 830-1998, IEEE Recommended Practice for Software Requirements Specifications”, October 20, 1998.

Table 5.10b Software Requirements Specification – External Interface Requirements

<b>External Interface Requirements</b>	
User interfaces	A first-time user of the app would be able to record details of patient history, side-effects, medication details (name, time and dosage), diet restrictions (no salt, no fat), diet advice, exercise time, and advice. User need to follow instructions on the screen and input through keypad, image or video. Design consideration in this research – bigger font size so it is easy for older adults to read.
Hardware Interfaces	Since the app is a mobile application, it does not have any direct hardware interfaces.
Software Interfaces	The mobile app is developed as browser-based and android app. Browser based can be accessed on any phones and android version to be used for minimal internet connectivity.

*Table 5.10c Software Requirements Specification – Overall Description*

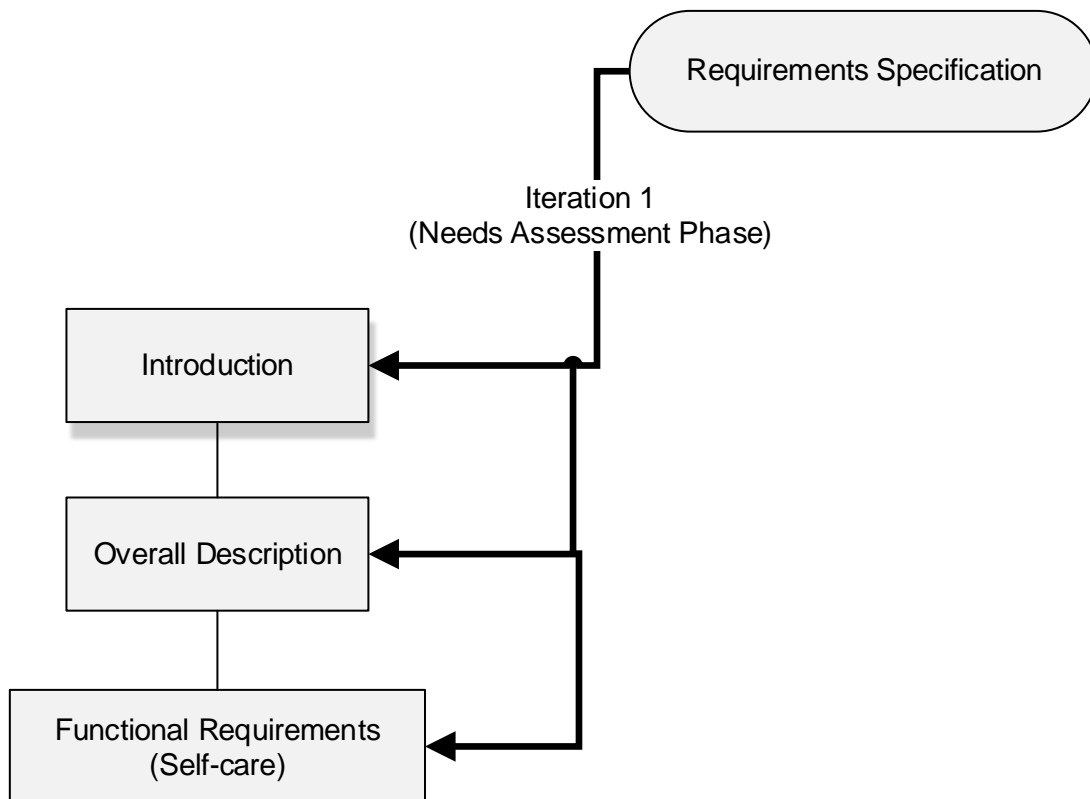
Overall Description - Provides the overall description of the system to be developed.	
Product Perspective	The system will consist of a mobile application for storing and retrieving data on treatment adherence. The system can be used anytime, anywhere as it is a mobile application.
Product Functions	Provide effective support for self-care management that will: <ul style="list-style-type: none"> <li>• Address patient needs for treatment adherence by reminding patients on medication and diet.</li> <li>• Help patients to recall the advice given by doctors.</li> <li>• Help patients in recognizing decision situations and plan for prevention.</li> <li>• To achieve the above functions the system aims to:</li> <li>• Improve (patient) self-awareness for treatment adherence.</li> <li>• Reduce risks with decision making.</li> <li>• Shared decision-making (between GP, patient, caregiver and other health professionals) as shown in section 5.4.4.</li> </ul>
User Characteristics	People diagnosed with CVD. Age: 49 upwards Gender: Male and Female Educational level: Any Special skills: Exposure to mobile or computer
Design and Implementation Constraints	Physical limitations: User should be able see the mobile screen. We also expect some manual dexterity to use a mobile phone.
Operating Environment	This research uses mobile phone apps as it enables patients to easily access and record information daily. Also reminders seems to be crucial for treatment adherence, hence mobile phones can remind patients anytime, anywhere.

The functional requirements in Table 5.10d shows the requirements based on the patient focus group studies presented in Tables 5.4-5.6. For successful everyday self-management patients need to maintain treatment adherence in terms of diet, medication and exercise. Therefore, the functional requirements 1.0 – 1.10 holds highest priority in the implementation. As this chapter focuses on gathering patient needs and experiences, the software requirements are mainly for treatment adherence and less on decision making as patient are not really aware of self-care decision making.

*Table 5.10d Software Requirements Specification – Functional Requirements*

<b>Functional Requirements (Self-care)</b> This section specifies the functional requirements needed for supporting self-care based on the focus group studies as shown in the requirements section below.	
Functional Requirement 1.0	Title: Download mobile application Requirements: The user should be able to download the application through the mobile application store (not part of this project due to ethics) or through a link.
Functional Requirement 1.1	Title: Diet Side Effects Requirements: Table 5.4
Functional Requirement 1.2	Title: Diet Regime (including alcohol) Requirements: Table 5.4
Functional Requirement 1.3	Title: Diet Advice Requirements: Table 5.4
Functional Requirement 1.	Title: Diet Reminders Requirements: Table 5.4
Functional Requirement 1.5	Title: Medication Prescription Requirements: Table 5.5
Functional Requirement 1.6	Title: Medication Reminders Requirements: Table 5.5
Functional Requirement 1.7	Title: Medication Side Effects Requirements: Table 5.5
Functional Requirement 1.8	Title: Exercise Requirements: Table 5.6
Functional Requirement 1.	Title: Exercise Advice Requirements: Table 5.6
Functional Requirement 1.10	Title: Exercise Reminders Requirements: Table 5.6
Functional Requirement 1.11	Title: Information Access Requirements: Access to information sources for patients to gain additional support (section 5.4.4).
Functional Requirement 1.12	Title: Shared Decision Making Requirements: Ability to record advice from doctors and other from other sources (section 5.4.4).

A summary of the first iteration of software requirements specification is shown in Figure 5.2. This figure will help to identify the different requirement specifications extracted in the CISDA phase in the following chapters.



*Figure 5.2: Software Requirements Specification in Iteration 1*

## 5.6 Phase Summary

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Studies I and II show that patients make a lot of decisions with regards to treatment adherence like side-effects, what to eat, doing exercise are uncertain, ill-structured and are time constrained. These studies with patients has helped to gather the Software Requirements Specification (section 5.5) to understand “How do patients actually self-manage in day-to-day life?” This phase also provides insight into “What decisions do they make in day-to-day self-care?” but does not fully address the research question: “How to describe everyday decision making for software design and development?” The study shows that:



- Patients are not fully aware of making decisions due to ill-structured problems and uncertainty patients' decision making process cannot be clearly extracted, as it is unclear as to:

1. How decisions patients make?
2. What are their decision problems?
3. What is their decision making process? Or
4. What is involved in their decision making process?

This chapter forms the groundwork to further explore the research question in Chapter 6:

How to describe everyday decision making for software design and development?

## CHAPTER 6 PHASE II THEORY FORMATION

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*“Decision researchers were trying to reduce errors, which is important, but we also needed to help people gain expertise and make insightful decisions.” - Gary Klein, *Seeing What Others Don't: The Remarkable Ways We Gain Insights**

This chapter provides guidelines for the designers to help in the implementation process followed by a case study example. The purpose of this chapter is to propose a descriptive framework for extracting requirements to support everyday decision making. The descriptive framework is based on the ideas from Naturalistic Decision Making and consultation models used by doctors followed by medical practitioners for supporting patient’s decision making. Twenty decision case scenarios were collected using a questionnaire study from CVD patients concerning a range of decision scenarios they face on a daily basis to evaluate the descriptive framework.

### 6.1 Theory Formation Phase Guidelines

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This section provides guidelines for decision aid designers to carry out the theory formation phase derived from the CISDA process. This phase along with the insights gained from previous phase (needs assessment Chapter 5) explores the research question 1: “How can we describe everyday decision making of CVD patients?”

#### **Purpose**

The purpose of this activity is to develop and apply decision theory to extract requirements for self-care decision making including functions and characteristics to help in the development of decision aids. This phase helps in understanding how doctors help patients in their decision making using consultation models; apply the ideas from Naturalistic

Decision Making and the normative approaches used by doctors in supporting patient's decision making. Alternatively, designers can apply multiple theories for further analysis as shown in the literature review or apply the descriptive framework developed in this study for understanding decision making to save time.

## **Thesis Composition**

This phase consists of:

- Decision Making Background – provides background on the consultation models used by doctors in supporting patient's decision making and relation to theories.
- Theory for Decision Making – analysis and applies naturalistic decision theory.
- Study: How Doctor's Support in Patients' Decision Making – interview studies to understand how doctors would support patients in their decision making process using case scenario presentations.
- Theoretical Framework for Describing Decision Making – forming a descriptive framework to describe patient's decision making.
- Evaluation – Patient's Decision Scenarios – evaluation of the framework using 20 case scenarios gathered from patients using questionnaire study.
- Software Requirements Specification – extraction of requirements for supporting decision making.
- Phase Summary – summary of this phase.

## **Methods**

This phase uses:

- Interview (section 4.2.2) using thematic analysis
- Questionnaire (section 4.2.3) using quantitative analysis

In addition to the above methods used in this thesis observation (Sekaran 2003), ethnography (Helander 2014), control task analysis (Gordon and Gill 1997) and user task analysis (Diaper et al., 2003) can be used to gain further insight.

### **Participants**

- Doctors working in primary healthcare centers or private practices in the UK.
- Patients diagnosed with CVD from BHF and local heart support groups.

### **Outcomes**

Software requirements specification for supporting everyday decision making by patients based on the theoretical framework derived from the doctor's consultation model and Naturalistic Decision Making theory.

### **Quality Criteria**

1. Does this phase apply appropriate decision theory for describing decision making?
2. Is it possible to develop a conceptual model representing the attributes and functions needed for the development?
3. Is the conceptual model adequate enough to map personal stories or case scenarios?
4. Does this phase provide appropriate details for understanding and designing decision making?
5. Has the theory or conceptual model tested with the users using real decision making scenarios or personal stories?

### **External Dependencies**

Patient participants or doctors to review the conceptual model.

## 6.2 Decision Making Background

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Literature on decision making is voluminous and extremely varied (Bandyopadhyay 1977), with various theories to explain decision making. Decision theory is an analytic and systematic approach for understanding decision making and application of decision theories help to describe and explain the behaviour to predict decision making (Durand et al., 2008). But, there is little evidence for extracting the requirements for supporting decision making including the functions needed for developing DAs. For instance, if a software engineer has to develop a system for enrolling students into a course, then s/he should know the attributes for the course (like name of the course, fees, duration, start and end dates) and student (student, gender, and country). This lack of knowledge may be cause of failure of DAs in providing effective assistance to patients (Power 2011). Moreover, in a review by Arnott et al., (2004), it was found that half of the published research on DAs was not grounded on judgement and decision making research. In another review, Durand et al (2008), found that the interventions that were described as “theory-based”, did not clearly specify the theory had shaped the design. Paterson et al., (2001) emphasis on the need for a new conceptualization of self-care decision making in chronic illness to address the unique and complex nature of everyday decisions.

Chapter 1 (section 1.1.1) and the study with patients (Chapter 5, section 5.4.2) shows that patients face various decisions that are ‘to do’ or ‘not to do’ with something in everyday self-management. But as patients were unaware of making decision, studying decision making with patients again was not found appropriate. Entwistle et al. (2004) study also identified similar decisions on observing patient’s participation in routine practice. For example, the study found out that patients booked an appointment to see doctors to ask, ‘if they can give

up ginger biscuits' or 'change diet'. As doctors (general practitioners) were the first point of contact for patients, the decision making study starts by exploring the doctor's consultation model.

### **6.2.1 Doctors Consultation Model for Patient Decision Support**

Models of patient-doctor decision making can be: Paternalistic decision making (or doctor-led, in which the GP chooses the treatment option and informs the patient), shared (in which the GP collects information from the patient and then makes a decision with the patient, considering any values, beliefs and preferences of the patient); or Patient-led (where patients make treatment decisions) (Wirtz et al. 2006; Emanuel & Emanuel, 1992; Charles, 1999; Laine & Davidoff, 1996; Charles, Gafni, & Whelan, 1997). Doctor's decision making is guided by various consultation models as discussed by Pendleton et al., (1984); Kurtz et al., (1998); Wirtz (2006); Crossley and Davies (2005); Levenstein et al., (1986). These models are mainly aimed at the following tasks:

1. Problem: Define the reason for the patient's attendance.
2. Situation Assessment/Information gathering: Including history, nature of the problem, and preferences.
3. Diagnosis/ Examination: Physical examination, assess condition, continuing problems and at-risk factors, understanding illness
4. Options: Ask the patient to choose an appropriate action for the problem.
5. Evaluating: Achieve a shared understanding of the problems by evaluating options.
6. Planning: Involve patient to share their preferences, negotiates for a mutually acceptable plan.
7. Follow up and establish or maintain a relationship with the patient.

These models help in understanding decision making with the doctors. As mentioned in Chapter 1 and 5 patients face various decision making in everyday self-management.

## **6.3 Theory for Decision Making**

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Similar to patient-doctor decision making, there are some studies to explore how people make every day self-care decisions for chronic illness. This section helps to summarise the current study on self-care decision making, the theory applied for the identification of the functions needs for DAs development.

### **6.3.1 Overview of Patient Decision Making**

Some of the studies on chronic disease decision making have provided a conceptual model or workflow to describe decision making (Moser & Watkins 2008; Klein 2008; Lipka et al., 2008; Endsley et al., 2007; Riegel et al., 2013; Riegel and Dickson 2008). For example, Moser and Watkins (2008) show that decision making is affected by many factors like psychosocial status that includes depression, anxiety, socioeconomic, perceived control and education; and aging status that includes: cognitive status, sensory impairment, comorbidities, and functional status. Klein (2008) study provides a workflow based recognition-primed decision making. In this study, the workflow mainly consists of assessing the situation, recognition of the situation, formulation of a mental model and implement the decision. O'Connor et al., (2003) identifies some of the key issues in decision making are: the types of decisions patients face; processes used to make decisions; decisional conflict/ options patients experience; roles patients take in decision-making; preferred types and sources of information about options; and criteria patients use to judge that a decision is satisfactory. These studies reflect the complexity involved in decision making as mentioned

in Chapter 1 (section 1.2). Some of the commonly used characteristics based on doctor's consultation model tasks (6.2.1) and decision needs identified in Chapter 5 (Tables 5.6-5.9) are listed in Table 6.1.

*Table 6.1 Decision Tasks, its Characteristics and Examples*

<b>Tasks</b>	<b>Characteristics (Chapter 5 studies)</b>	<b>Examples (Chapter 5 Tables 5.6-5.9)</b>	<b>Reference</b>
Decision Problem	Presents symptoms of the problem which are ill-structured, uncertain dynamics, and time-constrained.	"A bit unsure (to do exercise)." (ill-structured problem) "Feel a afraid to do exercise" (uncertain with changing dynamics) "Forgot to take medication" (Time-constrained)	Dickson et al (2007), Witt et al., (2012)
Situation Assessment/ Information gathering	Situational cues, symptoms, identify the causes, and past experiences.	"When to stop?" "Do I take more insulin of not?" When insulin levels are high, patient encounters decisions like: "What did I eat?"	Klein et al., (1993), Lippa et al (2008), Endsley et al., (2007), Riley and Arslanian-Engoren (2013), Riegel et al., (2013)
Diagnosis/ Examination	Making sense of the patient's presenting the health concern.	"Is it alright to get out of breath?"	O'Connor et al., (2003)
Options	Presentation and comparison of options	"What you can eat?"	Witt et al., (2013), Klein et al., (1993), Witt et al., (2012), O'Connor et al., (2003), Feldman-Stewart et al., (2013)
Evaluation	Clarifying values and preferences	"With Statins you are not supposed to have grapefruit"	Witt et al., (2012), O'Connor et al., (2003), Riegel et al., (2013)
Planning	Plan generation, managing illness	"What you can eat on a daily basis?" "Constant reminder for medication" "Reminder for dietary requirements"	Endsley et al., (2007)
Follow-up	May include need for further information, waiting for results or schedule consultations, etc.	"Medication intake timing"	Paterson et al., (2001)

Table 6.1 shows that self-care decision making is influenced by contextual elements like situation assessment that fall outside of traditional elements (Strachan 2014). The factors shown in Table 6.2 are similar to Klein and Hoffman (2008) macrocognitive models that describe the major goal- directed functions of cognitive work (problem identification,



situational assessment/ sensemaking, options evaluation, planning and replanning, and so on). These factors could be considered as the functions “Situation assessment, diagnosis, options generation, evaluation” needed for the design and development of DAs. These functions are referred in the decision literature as the macrocognitive models that form a key aspect of sociotechnical work systems to help systems and software engineers as well as cognitive systems engineers to develop a high-level understandings of the nature of cognitive work and can increase the likelihood of creating user-centred technologies and work methods. There is a need for considering macrocognition in the systems development so that technologies can augment human cognitive abilities for recalling experiences, managing attention, projecting trajectories, and achieving common ground to help people anticipate surprise and error – while preserving the clinical experience among clinicians and patients. So the next challenge is finding how decision theory can support the tasks and characteristics shown in Table 6.1.

### **6.3.2 Naturalistic Decision Making**

Durand et al., (2008) analysed over 50 decision aids but only 17 (34%) were based on a theoretical framework, 11 used decision-making theories described but the extent to which the decision theory informed the development was highly variable. Table 6.1 shows that self-care decision making functions for the development of DAs involving; identify decision problem, access the decision problem, and to recognise as part of their self-care decisions when to seek medical care (Riley and Arslanian-Engoren 2013). The macro-cognition shown in the previous section grew out of work in Naturalistic decision making (NDM) that uses cognition in settings that are like to be ill-structured, uncertain, time-constrained, etc., (Klein and Lippa 2008). Hence, self-care is described as a naturalistic decision-making process occurring in real-world settings which includes specific behaviours focused at maintaining health and well-being (Riegel and Dickson, 2008; Riegel et al., 2009).

Moreover, NDM model places emphasise on “How patients make decisions?” using a descriptive approach rather than “How patients should make decision?” as the significance of context is on understanding the various factors involved in determining the cognitive processes using the factors in Table 6.1 (Broadstock and Michie 2000). Hence, self-care decision making in this thesis is approached using a naturalistic perspective as it reflects real-world settings based on past experience and knowledge rather than on what ought to be done, or is normally, done in a specified situation (Riley and Arslanian-Engoren 2013). Although patients’ decision problem can be described as a multi-attribute space, in day-to-day life, it is unlikely that decisions will involve formal multi-attribute decision analysis. For example: in deciding whether to take an extra diuretic dose or not – patient may use a wait-and-see approach or do nothing until it is an emergency situation or may be make a decision depending on the patient’s experience, knowledge, situation or other factors (Riegel et al., 2013). Similarly, while considering risk related to shortness of breath - if allergies are recorded as the modest cause and physical activity has a significant value then within the rough set approach if no preference is given to one of them with respect to the attribute 'risk' it will not guide the patient properly. Also, if a CVD patient experiences discomfort in the chest, the patient might arrange for emergency admission as chest discomfort is endowed as the major cause for heart problems even though it might be due to gastritis.

Rather than solely applying rules or heuristics, Naturalistic Decision Making assumes that decision makers will frame the situation in order to allow them to draw on their experience and commit to a course of action. Moreover, the previous section shows NDM application for CVD decision making as the knowledge gained from experience on the part of the decision maker plays a crucial role in the decision process for recognizing situations, determining what information is relevant to the decision, and in deciding what would be an appropriate course of action. Self-care in everyday situations includes specific behaviours

aimed at maintaining health and well-being (Graven and Grant 2014; Riegel et al., 2013; Lipshitz et al., 2001; Dickson et al., 2008; Cameron et al., 2010; Cocchieri et al., 2013; Lee et al., 2013; Riegel et al., 2009). Therefore, decision makers will frame the situation in order to allow them to draw on their experience and apply known courses of action.

As suggested by Klein and Zsombok (1997) NDM self-care decision aids should be able to support decision processes familiar to the decision maker and the system can “think” more like a naturalistic decision maker by studying what people do. For instance, traditional rule based approaches may not be applicable because the number of interacting variables and the problem of fully quantifying conditions can be very difficult. While approaches using probabilistic reasoning could deal with some of this uncertainty, there remains the need to fully specify all of the possible factors to include in the rules. Self-care by patients can be conceptualized as a cognitive and behavioural process involving the choice of behaviours that maintain physiological stability including symptoms monitoring, treatment adherence, and response to symptoms (Lipshitz 2001; Sayers 2008; Riegel et al., 2009). The studies in decision making have described patients’ decision making using NDM (Haas 2006; Klein and Lippa 2008; Klein et al., 2003; Riegel et al., 2009). As patients’ decision making shares NDM characteristics (Orasanu and Connolly, 1993), and naturalistic decision making about conditions and symptoms better describes how a layperson makes decisions about their symptoms (Riegel et al., 2009).

Although NDM could help to further understand the application of the functions for supporting decision making, it is still unclear as to what attributes are involved in “situation assessment” or “diagnosis” for the development. This needs to be explored by studying the features and process doctors’ use in supporting patient’s decision making (Witt et al., 2012; Bonner et al., 2014).

## 6.4 How Doctor's Support in Patients' Decision Making (Study III)

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The purpose for this study is to understand how doctors aid in patient's decision making, what features and attributes they apply in supporting the factors/ functions identified above.

### 6.4.1 Method and Participants

Doctor's decision making study is carried out by conducting interviews based on case scenarios as shown in Table 6.2. The case scenarios were developed as mentioned in Chapter 4(section 4.5). Eight doctors (5 GPs and 3 Consultants) were willing and able to participate in the study. As the main focus of this study is to understand how doctors support patient's decision making, the interviews were conducted with 'only' GPs until a saturation point was reached. Four GPs were female and 1 male. The doctors have been practicing between 8-12 years. To ensure consistency, the GPs were presented with the same set of cases (see table 6.2).

*Table 6.2: Case Presentation*

Case 1: The patient is a 65 year-old woman diagnosed with CVD for two years. She has been feeling unwell and tired since yesterday.
Case 2: The patient is a 70 year-old man diagnosed with CVD for 5 years. The patient has been managing well but has been experiencing some pain in the chest since morning.
Case 3: The patient is a 60 year-old man diagnosed with CVD for a year. He recently had a bypass and due to increase in weight and poor exercise, he wants to change diet and exercise.

### 6.4.2 Data Collection

Each GP was interviewed for 30 to 40 minutes at a place and time suitable for them. The interview study was followed as given in Chapter 4 (section 4.3). All the five doctors received the same three patient cases (Table 6.2) and questions (Table 6.3). The questions are derived

from the characteristics/ factors in Table 6.1. The order of the cases and questions was the same for all doctors to reduce variations in difference of order.

### 6.4.3 Cases

To help frame the interviews, a set of three different patients' decision making cases were presented to doctors (Table 6.3). The case studies were developed as mentioned in section 4.5. Doctors were asked to reflect on all three cases in terms of how they would help patients to make decisions using Table 6.3 questions.

*Table 6.3: Questions used to elicit decision process*

Factors	Questions
Situation	How would you go about with the decision making based on the case?
Assessment	
Diagnosis	What are the things you would consider to diagnose the problem?
Options	Do you provide the options available for patients?
Evaluation	How do you evaluate the condition?
Planning	How do you plan treatment?
Follow-up	What about follow-up procedures?

### 6.4.4 Analysis

Notes were taken during the interview to capture doctors' responses. As the questions were based on the doctor's consultation model, the data from all the doctors were analysed by grouping together into a single cohort as mentioned in Chapter 4 (section 4.2.5). The text-based data were analysed using priori coding approach, to identify the potential coding categories based on the characteristics/ factors in Table 6.3. As it was as case presentation the doctors followed a doctor-led approach and as the interview used the same set of questions, it was easier to combine the feedback into a single cohort. During discussion, doctors indicated that they use a combination of decision models (or consultation models doctor-led or patient-centric or patient-led) depending on the patient expectations.

Table 6.4: Doctors' Support for Patient Decision Making

Case 1: Feeling Unwell (Table 7.3)		
Coding	Analysing Attributes	Example
Decision	Case 1 (table 1) Doctors' role for this case is to create self-awareness and reduce risks.	"This is the most common problem we face."
Situation assessment	Weight gain; Mood/ Feelings; Stress; Diet; New Medication; Sleep	"I will ask about periods (if female), weight gain, mood, diet, stress, or any medication that has been recently started"
Diagnosis	Patient history; Health condition	"We use a lot of intuition, clinical knowledge, and experience"
Options Generation	leaflets	"Give them leaflets, educate patients, tell them what is good and bad and leave the choice to the patients."
Evaluation	Patient preferences; Vital signs; rule out problems and risks	"Definitely patients decide."
Planning	Summarise their findings;	"We give them follow-up procedures."
Follow-up	Follow-up instructions	
Case 2: Chest Pain (Table 7.3)		
Decision	Case 2 (table 1)	"This might be due to various causes..."
Problem	Doctors' role for this case is to reduce risks.	
Situation assessment	Identify whether it is cardiac or non cardiac plural (lung related, musculoskeletal, gastritis); Information on pain; location; symptoms	"Depending on the condition of the patient you either diagnose or call the ambulance immediately."
Diagnosis	Patient history; vital signs; nature of the problem; patients' needs; concerns; health status; condition; call emergency for typical pain	"We follow a step-by-step approach to rule out non cardiac causes."
Options Generation	Provide advice and options	"Sometimes give them leaflets, so that they can take some time to think and decide with family."
Evaluation	Patient history; use intuition; clinical knowledge; experience with similar cases	"Sometimes patients have some preconceived ideas - they know what they want and they
Planning	Patients' preference; explain health conditions; develop treatment plan along with patients; encourage him/ her to accept responsibility	"Tell them your suspicion, and let them know that they need to be examined"
Follow-up	Give information about warning signs with follow-up procedure	
Case 3: Diet/ Exercise (Table 7.3)		
Decision	Case 3 (table 1)	
Problem		
Situation assessment	Patient's weight; cholesterol; BMI (Body Mass Index)	"We do some routine checks"
Diagnosis	Patient history	
Options Generation	Leaflets risks and benefits.	"Give them leaflets, educate patients, tell them what is good and bad and leave the choice to the patients." (Doctor 4)
Evaluation	Advice from rehab-nurse.	"Every-thing depends on patient's intellectual capacity, self-understanding about their problem and their needs."
Planning	Patients' lifestyle; Preoccupations; Encourage patients	"Unless they (patients) are motivated nothing can be done."
Follow-up	none	none

The implication of the comments is that a patient would be provided with a set of instructions relating to actions and compliance. From this perspective, problems could arise because patients do not follow the instructions provided; and the issue of compliance remains an important consideration in the management of CVD. One might assume that the role of a self-management system is, therefore, simply to enforce compliance and that this would be assumed to improve patient self-management. However, in a more patient-centred approach, the doctor focus was primarily on the ways in which patients could be provided with information. The categories used are exemplified with example quotes along with problem analysing attributes in Table 6.4.

#### ***6.4.5 Summary and NDM Implications***

The study implies that doctors recognize familiar and typical situations by using connections between features, events and memories. Doctors' decision making involves recognition of typical situations (in Case 2 Table 6.3) and course of action rather than comparing with options which is similar to Klein's (1993) Recognition-primed decision (RPD) theory, an example of NDM model. This also shows NDM quality like time stress. Doctors' decision making shows the importance of understanding situational assessment for understanding the problem that is critical to NDM researchers. In broad terms, doctors are seeking to collect as much information as possible.

Doctor's medical knowledge and experience (like the perceptual skills, diagnosis) of patients presenting with similar conditions, help to make fine discriminations or select appropriate heuristics to apply. This also shows the need to update knowledge based on action/feedback loops in NDM for understanding and differentiating the problem. What is more interesting is that this study implies the role doctors assign to their patients; or rather the suspicion that patients do not need to play a role in decision making but need to follow GPs direction and comply with instructions. The question is whether patients accept this role or whether they

continue to make decisions of their own (which might either run counter or parallel to the GPs guidance).

## **6.5 Theoretical Framework for Describing Decision Making**

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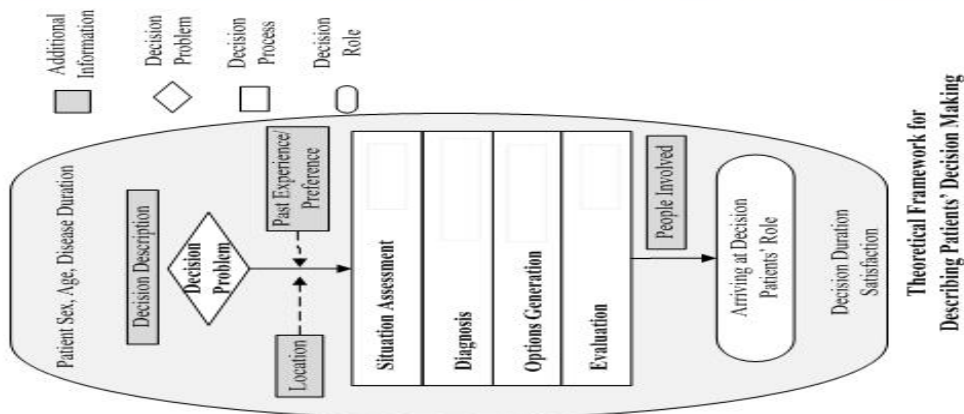
Based on the NDM factors and doctor's support for patient decision making, the features used to create a theoretical framework (Table 6.5) is to propose a generic approach for decision making, instead to look at the ways doctors' approach supporting patients' decision making. The framework is designed to figure out 'what strategies are used' and 'what context doctors think about'. The theoretical framework proposed in this section is derived from existing models (NDM and doctor's consultation models) as shown in Table 6.5 – Objectives. The descriptive framework consists of four stage analysis model (situation assessment – diagnosis – options generation – evaluation) for studying patients' decision making process.

Patients' decision making framework can help to tag information which is both physical and mental to re-organize the data for describing decision making as shown in Figure 6.1. Table 6.5 shows what exactly is involved in each stage along with the exploratory questions for finding patients' decision making. Additional information that can contribute to the understanding of decision making is also shown in Table 6.5 along with its objectives. To understand how the patient's decision making framework can help in describing decision making, Case 1 scenario (Table 6.2) and doctors' approach to supporting decision making (Table 6.1) is mapped to describe decision making.



Table 6.5: Proposed Theoretical Framework for Patients' Decision Making

Features	Objectives	Evidence - Doctors Study	Questions for Patients
Decision Problem	Define the decision problem.	Decision problem	What options did you have?
Situation Assessment	Nature of the problem, preferences, assembling information and assessing problem.	Vital signs, mood/ feelings, stress, diet, medication, sleep.	What were your feelings about this decision? What was your health condition?
Diagnosis	Consider history, identify attributes relevant to the decision.	Apply past experiences, patient history and health condition	Have you come across similar decisions before?
Options Generation	Compare and evaluate options using mental simulations rather than analytical comparison.	Provide leaflets and advice	Where would you find additional information?
Evaluation	Evaluate various options	Evaluate risks and benefits.	Are you clear about benefits?
Other Factors That May Influence Decision Process			
People involved	Involve patient and encourage responsibility.	Involve caregivers	Who was involved in making the decision?
Satisfaction	How satisfied the patient is?		Are you satisfied with your decision?
Patients' Details	To find significance between demographics.		Information on age, sex and disease duration.
Support and decision duration	The role other people play in decision making.		How can this person support you in following your course of action? Decision duration?
Patients' Role	Patients' role in decision making.		What role do you prefer in your decision?
Location	Where do patients mostly make decisions?		Where were you when you made the decision?
Preference and Past Experience	To identify patients preferences and help patient to apply past experiences	Consider patient preference and apply previous experience	Did you have a preferred option?



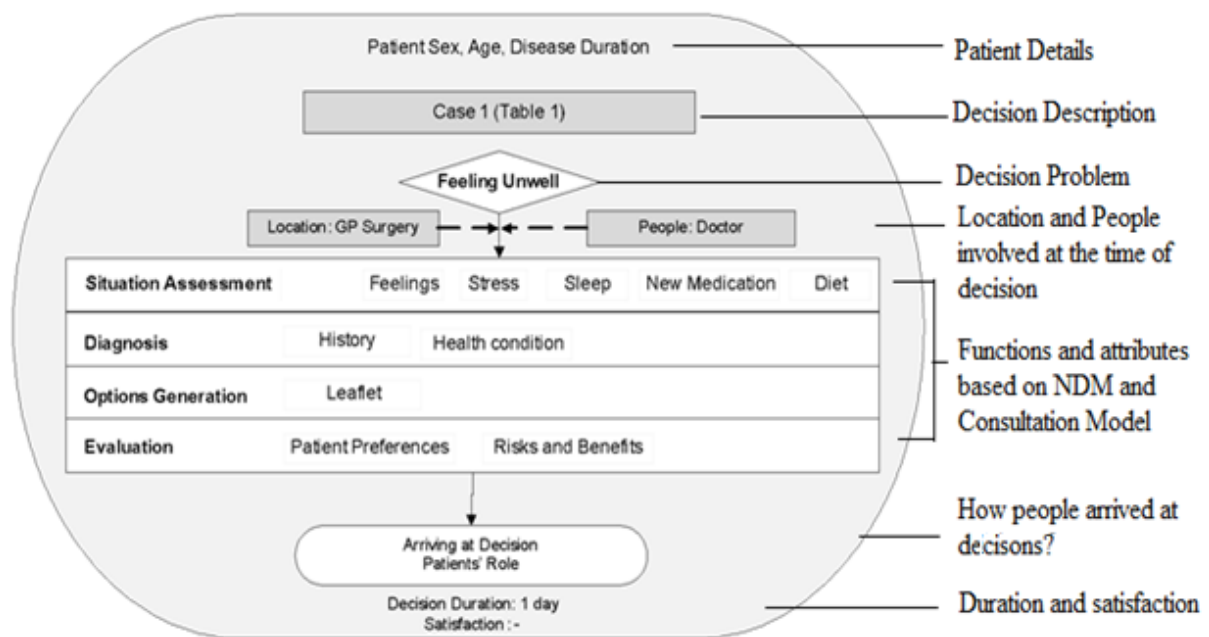


Figure 6.1: Doctors' Decision Making Process on Case 1 (Table 6.2)

This chapter has helped formulate or propose a theoretical descriptive framework for describing decision making to understand the functions and attributes needed for supporting decision making. It should be noted, of course, that no claims can be made as to whether the above scenarios represent a comprehensive description of all aspects of doctor's decision making. However, this framework (and subsequent assessment by the doctors) reflects the manner in which GPs support patients' decision making. The proposed framework is evaluated using patient's decision case scenarios in the following section.

## 6.6 Evaluation – Patient's Decision Scenarios

This section of the study focuses on evaluating the proposed decision making framework with patient decision making case scenarios.

### **6.6.1 Method and Participants**

Twenty patients diagnosed with CVD from the British Heart Foundation participated in this study. Participants were in the age range of 50-89. Each focus groups had 5-8 participants and were conducted on 4 different days in convenient locations. The study was conducted in two sessions. The first session was devoted to generating discussion on the various decision problems patients encounter in their everyday lives as patients were not aware of making decisions in day-to-day life. In the second, patients were asked to recall a decision problem they have experienced and to fill in the questionnaire. The questionnaire was designed based on the framework (Table 6.5) to identify the decision making process. The questionnaire was used so that individual case scenarios can be analysed to study the exact decision making process using the framework. Twenty patients participated in the questionnaire study.

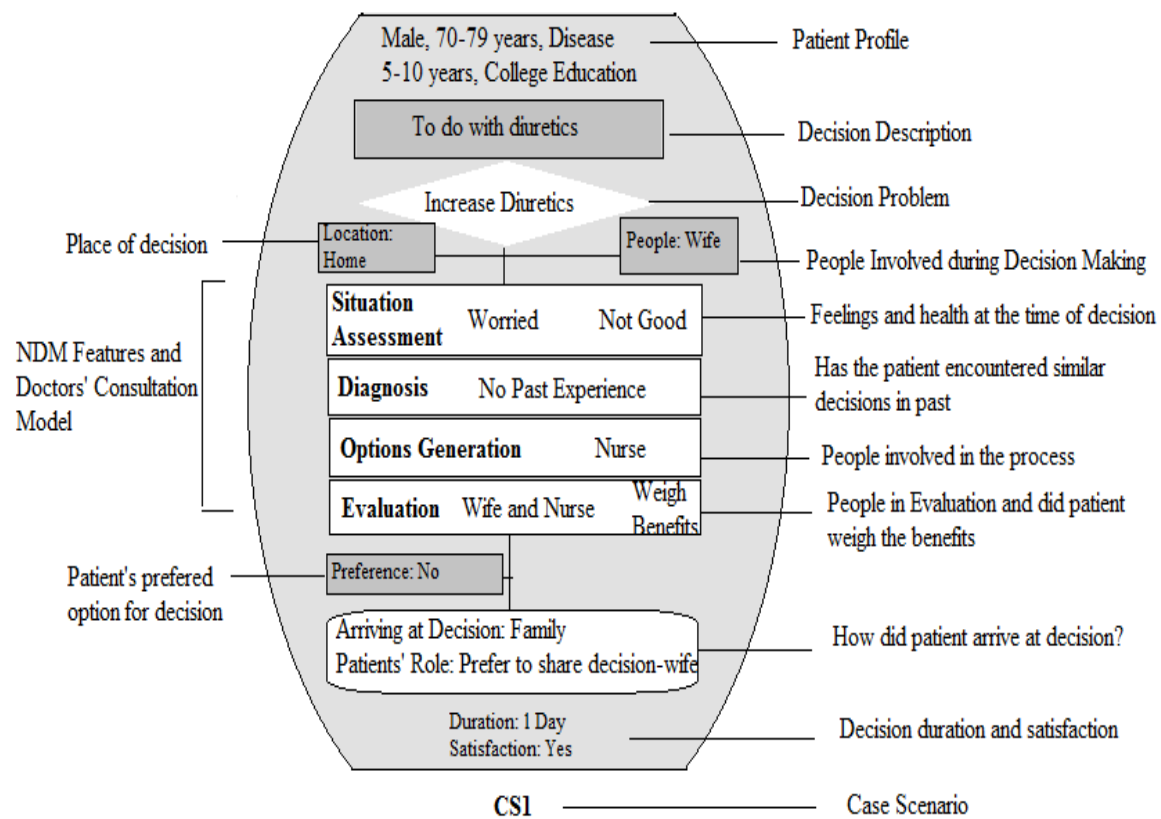
### **6.6.2 Analysis**

Participants were asked to start writing down their decision making process using the questionnaire, recollecting a decision scenario they had encountered. Each patient identified different decision making problems varying from pain to surgery and diet and exercise management. Altogether 20 patients participated resulting in 20 decision scenarios. Patients decision making were grouped based on the high level problems although there are some overlaps into:

- Medication
- Pain
- Diet and exercise

As each patients' questionnaire data represented a case study of the decision making process, it was mapped into the patients' decision making framework for analysis. As 20 decision scenarios (case scenarios) were collected, each of the decision scenario was given a unique

name, e.g., CS1 meaning case scenario 1 to CS20. Figure 6.2 shows the how the data gathered on the questionnaire is mapped onto the framework using Paint and Microsoft Visio tools. Similarly all the other case scenarios (Appendix H) were mapped as shown in the results section.



*Figure 6.2: Describing Patients Decision Making for Medication*

Figures 6.3 and 6.4 provides decision making with regards to pain, diet and exercise. Case scenarios in Figure 6.2- 6.4 and Appendix H shows how understanding of the decision making using the proposed patients' decision making framework helps to represent the type of decisions that are not typically studied to understand 'what decisions patients' make in everyday self-management?' or 'what is involved in everyday decision making'.

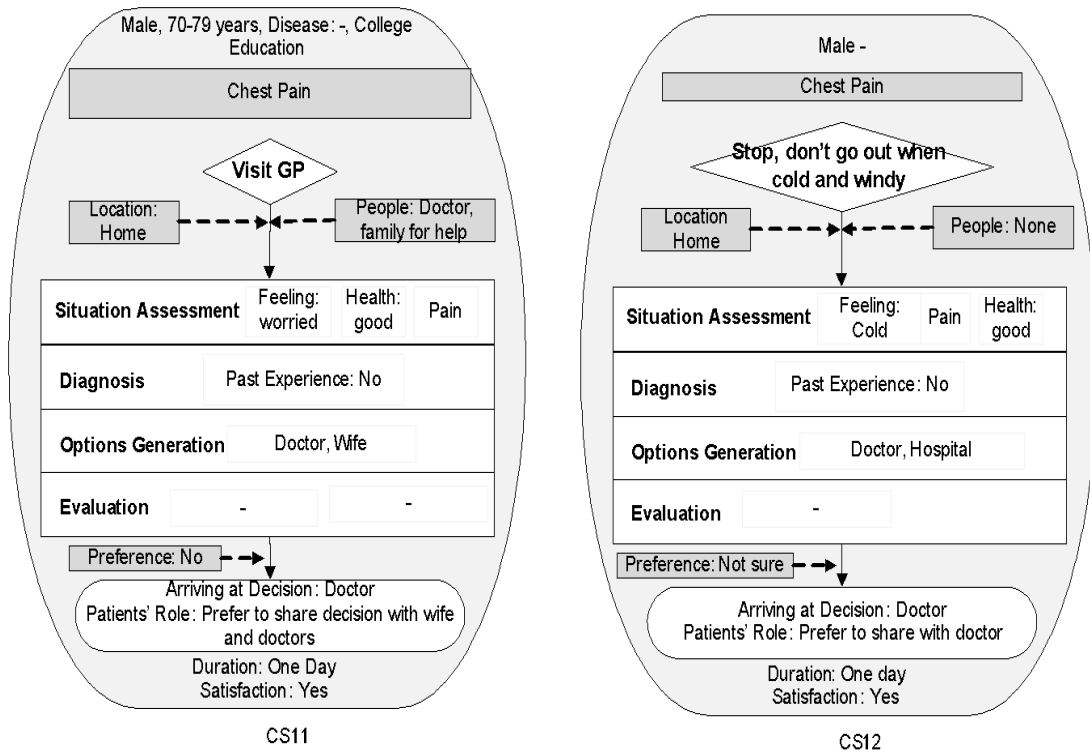


Figure 6.3: Describing Patients' Decision Making for Pain

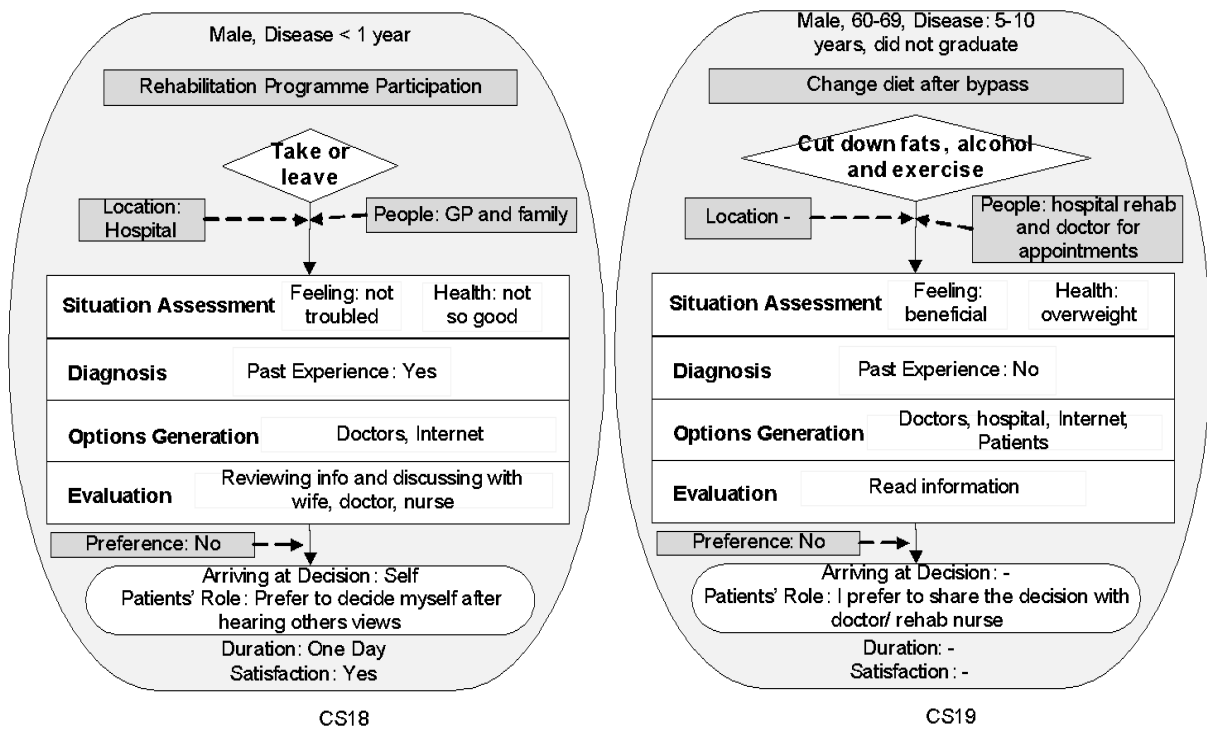


Figure 6.4: Describing Patients' Decision Making for Diet/ Exercise

### 6.6.3 Results

The results of patients' decision making scenarios are as follow:

- Decisions Relating to Medicine: 10/20 participants' decision making deals were related to medication.
- Decision Relating to Pain: 7/20 participants mentioned about their decision making process related to pain.
- Decision Relating to Diet/ Exercise: 3/20 participants mentioned about their decision making process related to diet/exercise.

Many features can intervene between the intent of the decision maker and the impact of the decision effects. The patient questionnaire data were mapped into the Theoretical framework (Table 6.5) to validate the framework derived for understanding decision making to help in the design of decision aids. This study shows the summary of the decision making includes:

- i. The decision context: Decision are influenced by:
  - Type of the problem: for example, pain, medication side effects, overweight, or surgery.
  - The decision maker: People vary in their role as decision makers. Some want all possible information whereas others are happy to rely on a doctors' recommendation.
- ii. Risks and Complications: patient decision making is very much associated with health risks and complications which may be short term or long term.
- iii. Health condition: 16/20 patient's decisions have been forced due to their health conditions.
- iv. Preference - 10/20 patients had preferred option and 2/20 were not sure, while the rest of the patients did not have any preference.

- v. Mood/ Feelings - Patients' feelings and experience with similar problems can also influence the way in which decisions are made.
- vi. Age: Due to the age of the patients and nature of the disease, patients need support from family / caregivers, doctors and nurse; hence most of the decisions have been shared.
- vii. Time: The time for making decision varied depending on the nature of the problem. For problems where the patients faced serious consequences, decisions have been taken within a day.
- viii. Problem: Most of the problems seem to be undefined with vague symptoms like "Feeling Unwell", "Sickness", and "Side effects – cough/ pain".
- ix. Context: Patients realized their decision problem mostly in their home, while some problems were taken outside home.
- x. Decision Maker: Due to the nature of the problem, patients' age and the effect, patients seem to depend on doctors for making their decisions.

#### **6.6.4 Summary**

This section helps to evaluate the proposed theoretical descriptive framework for describing and understanding decision making using 20 patient's decision case scenario. The case scenarios add to Chapter 2 review claim on whether current DA devices can be expected to support the type of activity that patients seem to be doing in relation to: medication, pain, diet, and exercise decision problems. For example: feeling unwell, pain, sickness, missing medication, and maintaining diet and weight.

The description of decision making shows that most of the decision option involved going to the doctor for intervention while few of the patient's option was to wait and see or to

experiment like in the case of CS3 and CS15 (Appendix H) as identified in Chapter 6. This does not mean that patients approach doctors for everyday self-management decision needs, as patients were asked to recollect one of their decision scenarios and provide with their approach for decision making they have tried to recollect a ‘typical’ decision scenario they could remember. As the focus in this study is to gather decision scenarios as much as possible to gain an understanding of decision making, this study has helped to find out ‘what is involved in everyday decision making?’ Appendix H shows that patients face various decisions relating to medication side-effects as mentioned in Chapter 5 and they seem to share the same characteristics like NDM as mentioned in Table 6.2 (uncertainty, lack of communication, ill-structured and not very specific like muscular pain).

## **6.7 Software Requirements Specification (Iteration 2)**

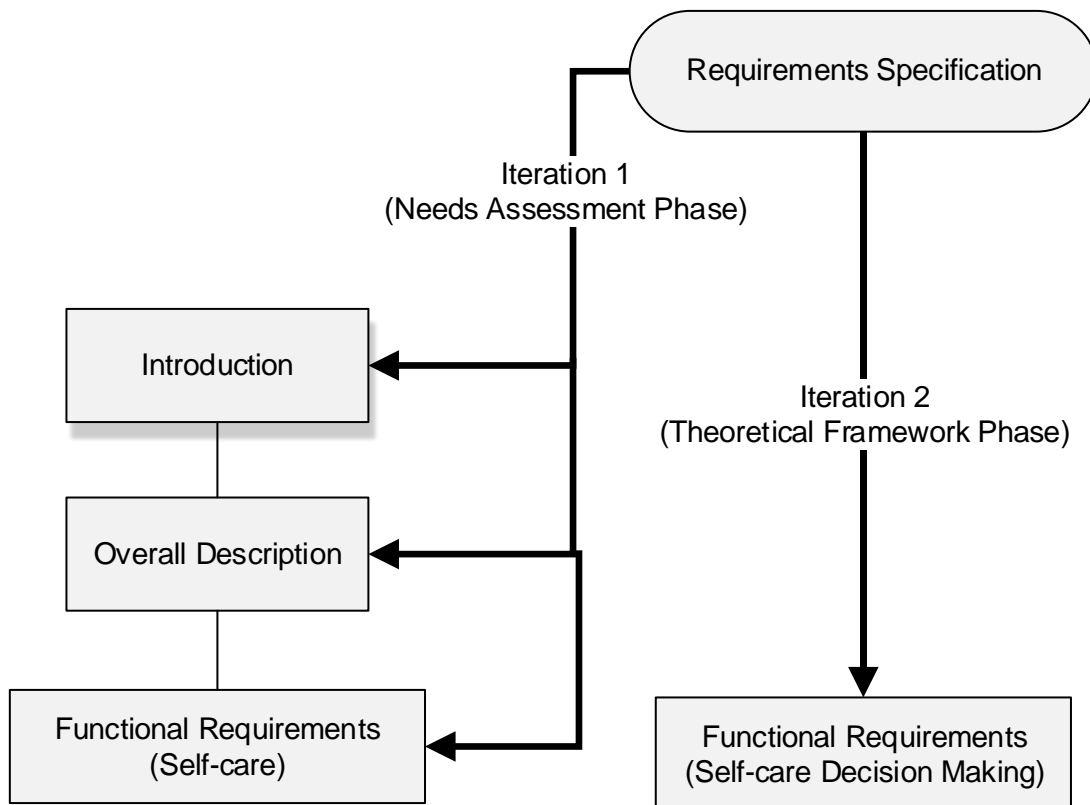
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Chapter 5 (section 5.5) provides a software requirements specification for everyday self-care management which is similar to the studies in section 5.2 this is because the studies (I and II, Chapter 5) did not provide enough details for understanding decision making. This phase proposes a descriptive framework for understanding decision making. For example, Table 6.6 functional requirements are derived from the theoretical framework in Table 6.5 which forms a continuation to the functional requirements in Table 5.10 (d). A summary of the software requirements from iteration 1 (Chapter 5, section 5.5) and this chapter is shown in Figure 6.5.



*Table 6.6 – Software Functional Requirements for Self-care Decision Making*

Functional Requirements for Self-care Decision Making	
Purpose: Software Requirements for Supporting Self-care Decision Making. This table is a continuation of the functional requirements (Table 5.10d )	
Functional Requirement 1.13	Title: Decision Problem Requirements: Provide a list of common decision problems for the patient to choose from.
Functional Requirement 1.14	Title: Situation Assessment Requirements: Help patient to assess the situation based on vital signs, mood/ feeling, stress, diet, medication, or sleep.
Functional Requirement 1.15	Title: Diagnosis Requirements: Help patient to apply past experiences, history, and knowledge for diagnosis.
Functional Requirement 1.16	Title: Options Generation Requirements: Provide access to information for comparing and evaluating the options.
Functional Requirement 1.17	Title: Evaluation Requirements: Evaluate risks and benefits.
Functional Requirement 1.18	Title: Record Advice (People Involved) Requirements: Help patient to record advice if need be
Functional Requirement 1.19	Title: Satisfaction Requirements: Gather patient's satisfaction on the decision made. This is not supported in the prototype but would be useful to gather patient's satisfaction in future studies to evaluate the decision process.



*Figure 6.5: Software Requirements Specification in Iteration 2*

## 6.8 Phase Summary

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Due to the complexity of every day decision making, it was difficult to extract decision problems and the process in the previous chapter as the patients did not realise that they were actually making decisions until they were given lot of examples and patients stories like the evaluation study in this chapter (6.6). Understanding of doctor's consultation model and NDM has helped to derive a theoretical framework for describing decision making to address the research question 1: How to describe everyday decision making for software design and development? On evaluating the validity of the theoretical framework, the Software

requirements in Chapter 5(section 5.5) has been revised to include the Functional Requirements (6.7.1) needed for supporting decision making.

The focus in this chapter was really on getting a good sense of decision making scenarios rather than an exhaustive catalogue of all experiences to understand self-management. This chapter has helped us to gather functional requirements for supporting self-care decision making but not much of information to find out the system-level view of the system to understand the people, their role, tasks, various courses of actions for extracting the performance requirements for the system which is the focus of Chapter 7.

## CHAPTER 7 PHASE III - MODELLING

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*“In the university, professors make up artificial problems. In the real world, the problems do not come in nice, neat packages. They have to be discovered.” - Donald A. Norman, The Design of Everyday Things.*

Previous chapters (5 and 6) helped to describe decision making and software requirements to support self-care management and decision making. This chapter starts with guidelines for the DA designers to help in the implementation process followed by a case study for this phase. This chapter provides insights into extracting and synthesizing ‘system features and performance requirements’ for decision making using CWA to decompose the complex decision making problem through the multi-stage analytical framework. As decision making can be influenced by skills, knowledge, experience and information/ cues available to patients, it is argued that patients require different forms of DA to support the performance requirements for different types of decision making: one design based on high level requirements; one based on a normative model of decision-making for patients; and the third based on a range of heuristics that patients seem to use. System Features helps in addressing the system needs for the decision aid.

### 7.1 Modelling Phase Guidelines

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This section provides guidelines for decision aid designers to carry out the modelling phase derived from the CISDA process. It was felt in the review of literature that majority of contemporary patient DAs focus on either specific problem in very high-risk areas or giving the “right” answer to the patients. To overcome this, there is a need to explore research

question 2: Can everyday self-care decision making be extracted and modelled for software implementation?

## **Purpose**

The purpose of this activity is to extract and synthesize decision making using CWA to decompose the complex decision making problem through the multi-stage analytical framework. This thesis uses CWA for modelling decision making as it fits in well with NDM decision theory and helps in modelling decision making using five stages to gain a systems-level view.

## **Thesis Composition**

This phases consists of:

- CWA Modelling – shows the CWA analysis using the requirements specification extracted in Chapters 5 and 6.
- Informal Feedback (Optional for designers) – gather feedback from experts in the field of HCI on this phase.
- Requirements Extraction – extraction of requirements using CWA analysis.
- Phase Summary – summary of this phase.

## **Methods**

The primary aim of Modelling is to extract requirements and to model patient's day-to-day decision making. In addition to the CWA analysis, further modelling could be carried out through UML extensibility mechanisms (Object Management Group OMG) to gain further insights into the process. UML provides lightweight extension mechanisms, such as stereotypes for CORBA IDL interfaces, constraints and tagged values (Kobryn 1999). There are also more demanding extensions, such as application frameworks and distributed business components to provide a high-level view of the system.

## **Participants**

- HCI researchers from IBM, HP and Microsoft India
- Presentation was done in their respective labs for 5 participants in IBM, 12 participants in HP and 19 participants in Microsoft.

## **Outcomes**

Analysing the decision process and extracting system features and performance requirements to support different types of decision making.

## **Quality Criteria**

1. Does the model map the environment, healthcare organization and people?
2. Is it possible to extract the various courses of actions for supporting decision making?
3. Does the model provide appropriate details for mapping the decision making process?
4. Has the model been tested to support real decision making process?

## **External Dependencies**

Validating the modelling approach with subject matter experts (optional).

## **7.2 CWA Modelling**

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The CWA modelling diagrams used in this chapter are supported by the CWA tool produced by Jenkins et al. (2008). Software Requirements Specifications from Chapters 5 and 6 (5.5 and 6.7) are used in CWA analysis.

### 7.2.1 Work Domain Analysis (WDA)

WDA describes the ways in which the ‘functional purpose’ of a system (on the first row of Figure 7.1) is achieved through the use of performance of specific actions on specific physical objects in terms of specific values and priorities held by the system. Overall the ‘functional purpose’ is to support ‘cardiac patients’ decision making that is achieved by the ‘system’ (which would include the patient and their carer(s), general practitioner and other healthcare professionals, medication, information sources etc.). Having defined the functional purpose, the next step is to define the ‘value and priority; measures of the system (the second row of Figure 7.1). These represent those aspects of performance that the system could use to indicate how well it is performing. From the needs assessment (Chapter 5.5.2.2) the values and priorities are: improved (patient) self-awareness; reduced risks; shared decision-making (between GP, patient, carer and other health professional); and managed information (refers to management of information in the system: resources and data capture).

The next step is to consider the physical objects (the fifth row of Figure 7.1) that the patients currently use to support their activity. As shown in Figure 7.1, Chapter 6 case scenarios collected from the questionnaire revealed that patient’s decision making depends on many things including:

- People e.g., doctor/GP, nurse, caregiver, patient.
- Physical objects such as leaflet, health-related websites
- Specific pieces of information such as sleep, feelings, side-effects (of medication) or quantity (of food, drink or medication) or status (of eating, drinking or taking medication), exercise.
- Previous experiences, problems, symptoms, reason and cause and options.

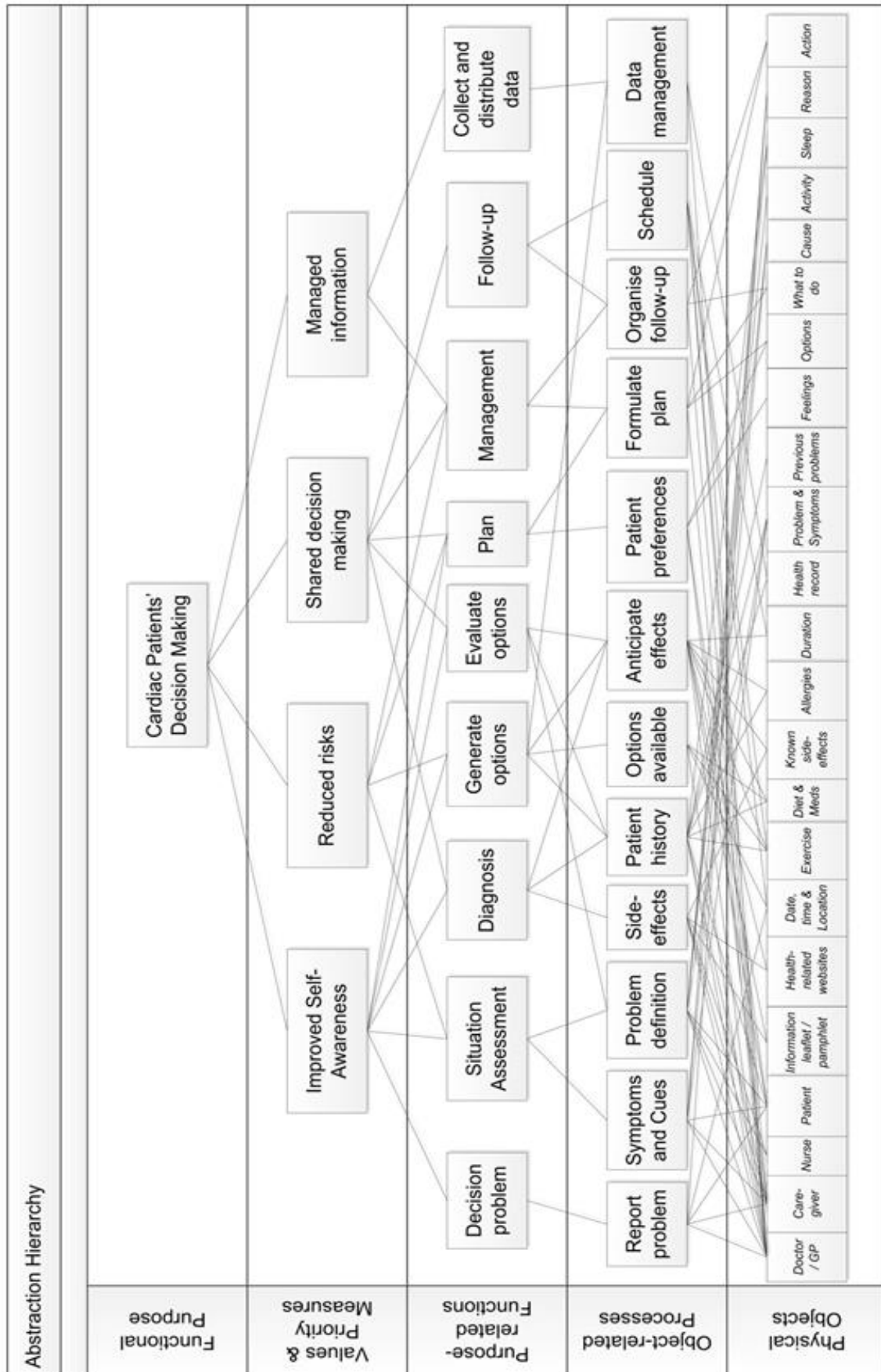


Figure 7.1: Abstraction hierarchy for Decision Analysis



Having defined Physical Objects, the next step is to see how patients make use of these Objects.

The Object-related Purposes are derived from NDM studies to further refine the case scenarios (Chapter 6) and define them:

- Report problem - As soon as patients encountered problem they sought medical attention as in CS1, CS2, CS3, CS4, CS10, CS11, CS12, CS13, and CS14.
- Cues - Patients have tried to identify the cues based on diet, medication and exercise for problems like CS2, CS4, CS9, and CS17.
- Problem Distinction - Try to isolate the problem (e.g., CS9).
- Side-effects - identify the side-effects based on the problem like in CS4, CS6, and CS9. This involves the requirements gathered in section 5.5 for diet, medication and exercise.
- Historic Information - CS7 and CS3 patients have taken into account their previous experiences.
- Options –patients have options in decision making e.g., CS15, the patients’ options were either to ignore the symptoms or to call the ambulance.
- Anticipation - CS9 patient decided to stop walking when it is cold and windy as it might affect him later on.
- Patient Preferences - CS19 shows that patient wants to cut down on fats and alcohol. Also patient prefer to seek advice from the doctors.
- Formulate Plan – patients seem to formulate treatment care plans like in CS5 on their own or with the help of doctor like in CS14 and CS16.

- Follow-up - CS13, CS11, and CS10 received follow-up procedures including what symptoms to watch out for and when to seek medical attention.
- Scheduling - Some patients sought medical attention immediately like in the case of CS3, who felt sick in a conference, while for other decisions like CS12 they go for scheduling.
- Data Management - This deals with data management.

Finally, the purpose-related functions link the object-related process to the values and priorities of the system and to the functional purpose (in the third row of Figure 7.1). In order to define purpose-related functions, the cognitive functions discussed in chapter 6, are used to represent a set of cognitive functions involved in patient decision-making.

Similar to representing the requirements for the decision process from section 6.7, AH is also formed to represent the requirements for self-care management (section 5.5) as shown in Figure 8.2 WDA helps to identify values and priorities, purpose-related functions, object related processes, and physical objects needed to support decision process. Moreover, the functional purpose in WDA refers to the total system and the individual physical objects represent the components or subsystems as shown in Abstraction Decomposition Hierarchy (ADH) Figure 7.2. The ‘total system’ manages the functional purpose. The system is made up of subsystems which, in turn, are composed of components. The abstraction analysis considers whether functions are most likely to be performed at the subsystem or the component level. This leads to the distribution of the functions, values and priorities in Figure 7.2 (for ease of reading the physical components level of the ADH not included).

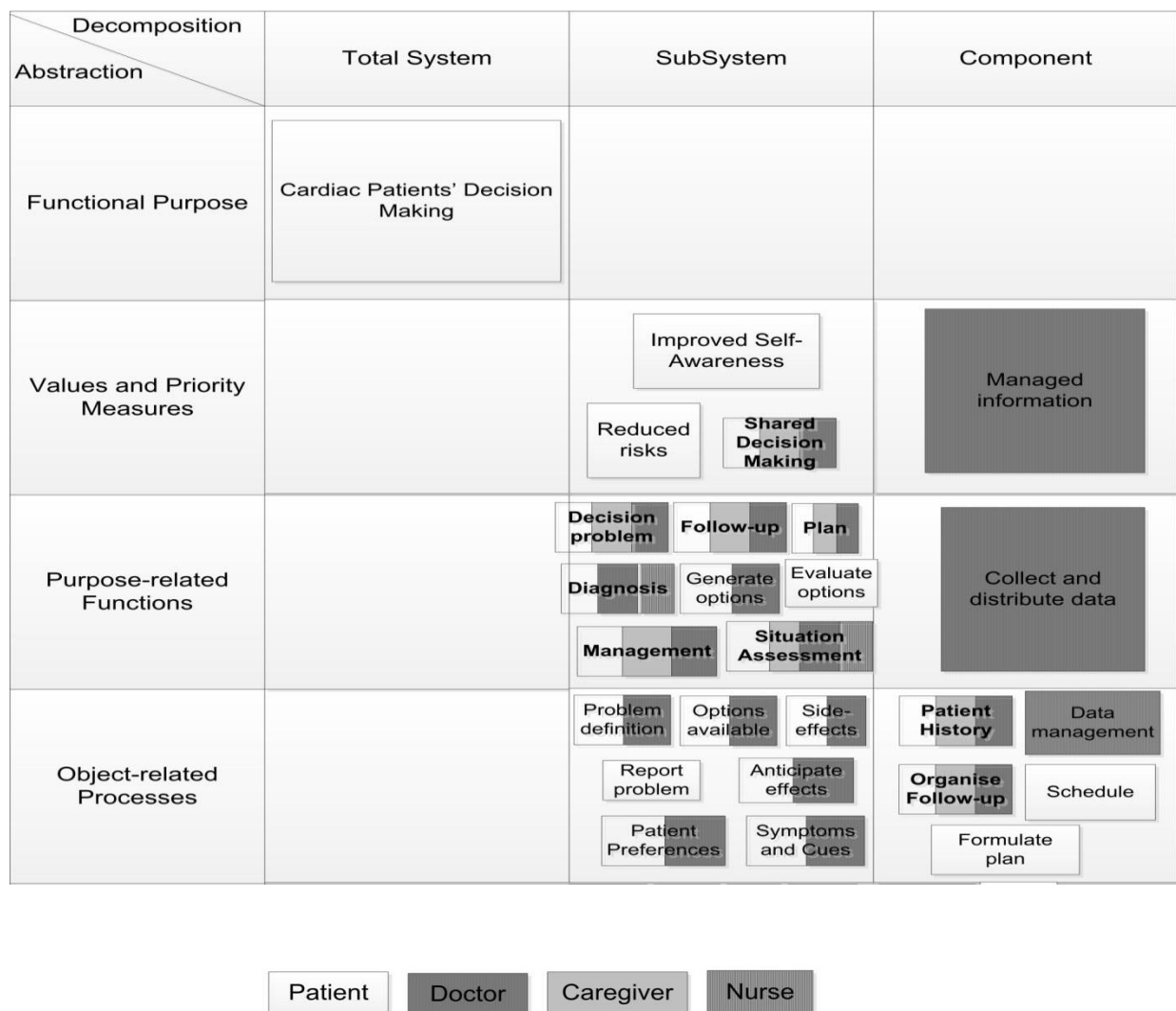
Typically, CWA is applied to industrial systems in which the concept of subsystem and component is self-explanatory; in this chapter, the division is less clear but the assumption

here is that a ‘component’ would involve an individual actor in the system whereas a subsystem would involve more than one actor. This abstraction helps designers to understand the patient’s environment in terms of part-whole relationship through several conceptual levels that range from abstract to physical (Effken et al., 2011). Each level in ADH provides a unique perspective of the same system to help the designer better understand the interaction between various resources and the information flow. WDA also helps the designer to understand what information is needed to accomplish the task goals and the implications for the design of DAs along with the underlying database and relationships (Effken 2002).

### **7.2.2 Social Organisation and Cooperation Analysis (SOCA)**

Chapter 2 shows the importance of considering work organisation – the roles and tasks of doctors, nurses and caregivers working with the patient. SOCA uses the ADH analyses to map actors to functionalities in Figure 7.2. For example: ‘decision problem’ can be performed by patients on their own or with the help of caregivers / doctor / nurse, hence in Figure 7.1, white shading for ‘decision problem’ refers to patient and ‘situation assessment’ refers to all the actors involved in the decision process.

From figure 7.2, one can see that there is scope for the purpose-related and object-related functions to be performed by either the patient or one of the other actors. In situations where there could be more than one actor performing a function, it is assumed that this could represent either a single individual performing the function or a combination of actors, perhaps in the form of a dialogue or collaboration. In terms of designing DA, this could be used to determine when a patient might need to make contact with one of the other actors and to allow the design to consider how such contact could be supported.



*Figure 7.2: Social Organisation and Cooperation Analysis*

### 7.2.3 Control Task Analysis ('Decision Ladder')

From the functionalities and processes captured in the Abstraction Hierarchy, the patients' decision making process can be described using the 'decision ladder'. This allows us to focus on what decision goal has to be achieved independent of how the decision task is conducted or who the decision makers are. To model the decision process 20 patients' decision scenarios based on AH functional purposes such as medication, pain management and diet/exercise were used for analysis. Four decision process scenarios CS7, CS12, CS15 and CS19 are presented and others are shown in the supplementary document as an example for illustration (Figure 7.3).

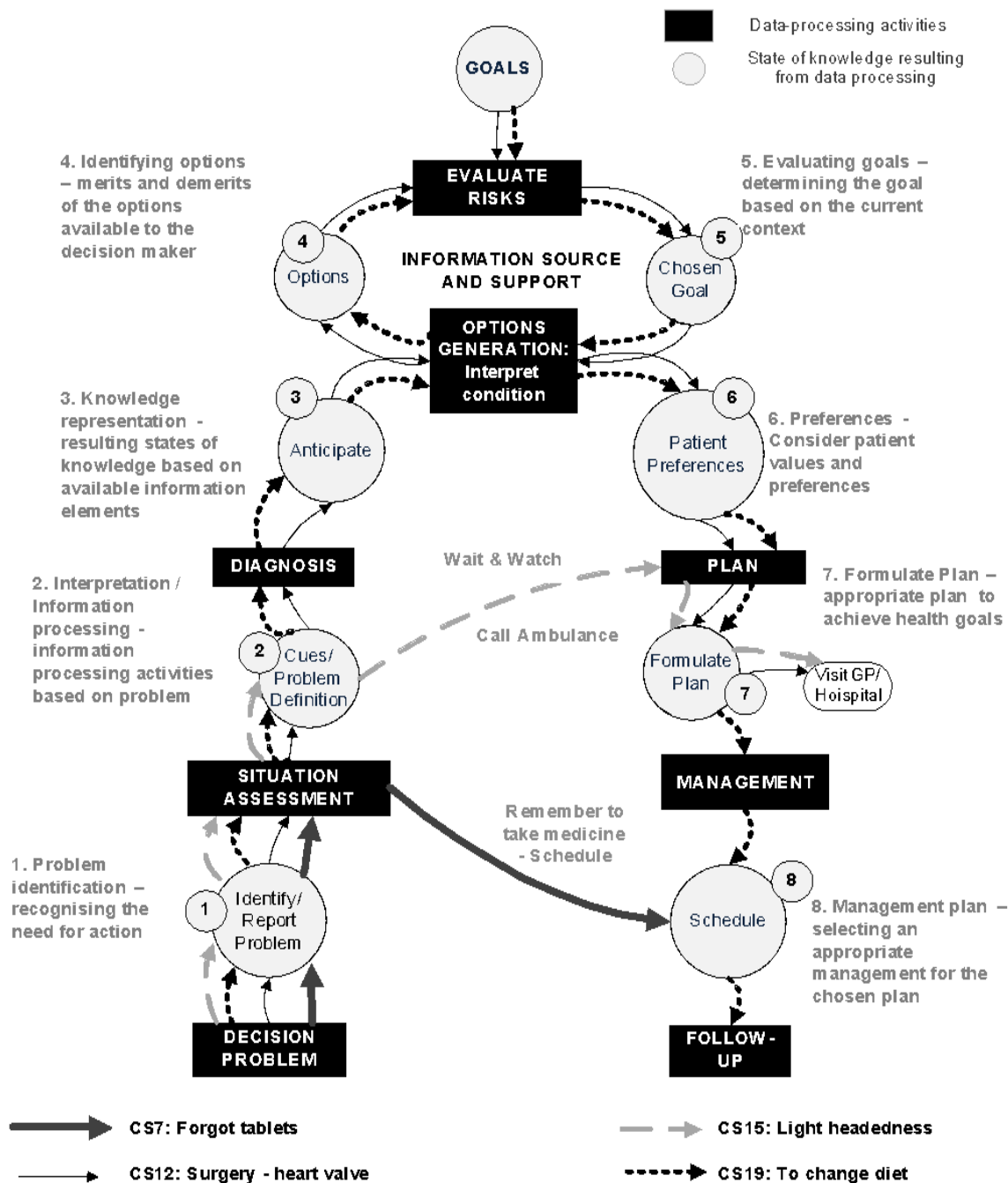


Figure 7.3: Patient Decision Making Process for Pain

The basic structure of Decision Ladder is defined by a series of states of knowledge and information processes arranged in a sequence that characterises rule, skill and knowledge-based behaviour. The decision ladder has 8 states of knowledge, shown as circles in Figure 7.3. These knowledge states arise from data processing actions which correspond to the

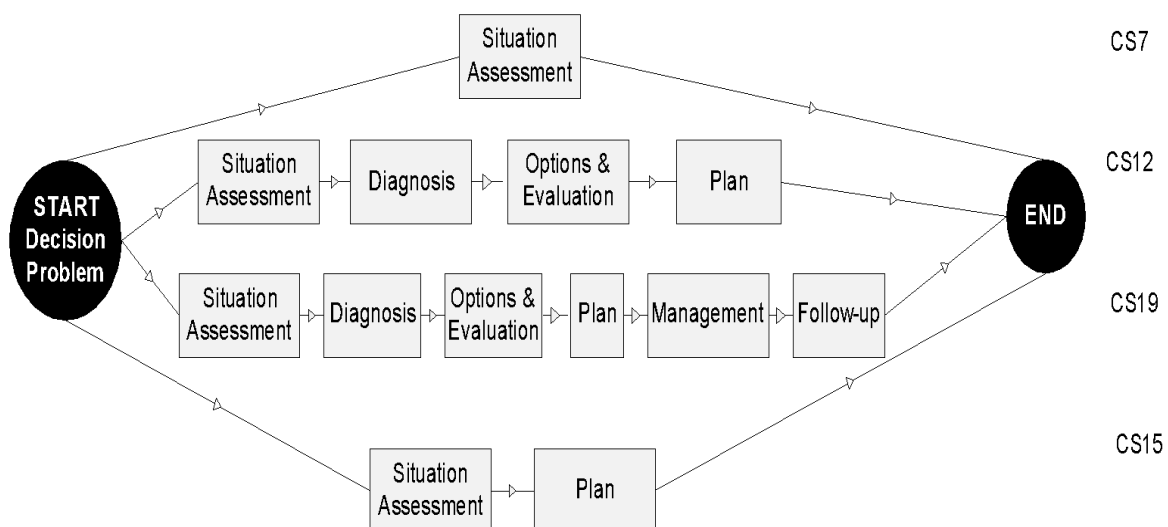
purpose-related Functions in Figure 7.1, performed by the decision maker (shown by boxes in Figure 7.3).

As decision ladder in this study is used to represent the processes involved in patient decision making, the names of activities have been modified from the traditional terminology used in the process industries to a more medically-oriented description. The dotted lines and the lines passing through the middle of the hierarchy labelled as “schedule”, “call ambulance” and “wait and watch” (Figure 7.3) represent the ‘shortcuts’ that patients took in their decision making based on their knowledge and experience. This implies that patients’ decisions are not always rule-based but can be influenced by skills, knowledge, experience and information / cues available to them. Although patient’s decision making can be described using decision ladder, it tends to be dependent on the nature of the problem and various factors including self-awareness, health condition, previous experience, and patient preferences. Due to these dependencies, each problem is considered to be distinct but the decision ladder analysis shows that due to the shortcuts the process seems to be similar. For example, the patient who has encountered decision problems like CS12 (surgery for heart valve) and CS19 (to change diet) has gone through the whole decision process including gaining additional information for planning and management. Whereas in CS7 (forgot tablets) the patient seems to have used his past experience to decide but in the case of CS15 (light headedness) the patient seem to have understood health cues before arriving at a decision.

Decision ladder analysis helps in the design of procedures to support patients in achieving their healthcare goals or to automate portions of these procedures (Effken 2002). The analysis also indicates which variables and relations of the work domain are relevant for a particular situation so the interface can be designed to present the right information at the right time for human-computer dialogues (Effken 2002).

## 7.2.4 Strategy Analysis

Decision ladder helps to describe patients' decision making processes starting from problem identification through to follow-up with various shortcuts. The next task is to contrast approaches to the decision problem in order to identify various courses of action or strategies that patients follow and to understand which strategies are possible for each of the decision problem. This is done using strategy analysis in CWA. Figure 7.4 provides example of some courses of action based on the decision ladder analysis along with the case scenarios to understand when patients need additional information for their decision problem and when patients would decide on their own. For example, when patient “Forgot tablets” like in CS7 the patient has immediately decided to remember to take medicine. In the case of “decided to change diet” like in CS19 the patient seem to have analysed the situation, has gone through the diagnosis and options evaluation stages before planning and management.



*Figure 7.4: Example Strategies Analysis based on Decision Ladder Scenarios*

The strategies analysis allows the designer to consider various courses of action to develop appropriate guidance and guidance for different strategies. At one level an essential aspect of self-care decision making is the ability to ask the right questions. Through the decision

ladder and strategy analysis, it is possible to develop a structured approach to asking questions to allow patient and DAs to reach a view.

### **7.2.5 Competencies analysis**

Chapter 1 specifies that patients use different learning process and their decision making is influenced by their skills, rules and the knowledge gained through their experience. This is also implied in the patient case scenarios (Chapter 6) from the Control Task Analysis and Strategies Analysis. Depending on the problem and patients' skill or knowledge the application of strategies or course of action differs. Therefore, it is important to find out what competencies and system constraints are needed to support decision making.

Competency analysis in this section is carried out using Vincente's (1999) study as a guide. Using this study, the competencies were analysed based on the studies conducted in Chapter 5 and 6. Competency analysis deals with the mapping between required competencies of patients and the system constraints, and is typically performed using Skill, Rule and Knowledge based human behaviours referred to as SRK taxonomy (Skill-based, rule-based or knowledge-based). The application of different SRK taxonomy are as follows:

- In skill-based behaviour patient's perception of the situation is mapped directly to the actions with no conscious behaviour control involved.
- In rule-based behaviour the patient is guided through a pre-planned sequence of actions.

In knowledge-based patient uses situation assessment, planning and reacting to contingencies. SRK information can be mapped with the decision ladder to understand patient's behaviour at a control task level (Rasmussen et al. 1994).



Table 7.1: Sample SRK inventory for Patient Competencies Analysis

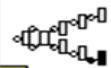
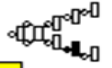
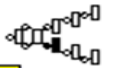
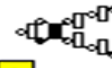

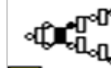

Information Processing Step	Resultant State of Knowledge	Skill-Based Behaviour	Rule-Based Behaviour	Knowledge-Based Behaviour
 <b>1</b> <b>Decision Problem</b>	Identify the need for making a decision	Decision problem would be cued internally and have an automatic response.	Recognition of automatic response	Recognise uncertainty and lack of knowledge
 <b>2</b> <b>Situation Assessment</b>	Access the situation	Apply pattern recognition and/ past experiences.	Comparison between normal and current state. Analyse situation using past experiences.	Problem identification considered against overall objective.
 <b>3</b> <b>Diagnosis</b>	Anticipate future states and the current situation.	Anticipate the future state based on health cues.	Monitor vital signs and gather health cues. Rule-out side-effects and other causes.	Investigate the situation using patient history, health cues and side-effects.
 <b>4</b> <b>Options Generation &amp; Evaluation</b>	Anticipation of the problem by comparing and evaluating the situation using information from various sources including doctors, hospitals, journals and more.	Evaluate the situation based on available information.	Evaluate the options available by considering the risks and benefits.	Recognise uncertainty and lack of knowledge by seeking additional information for considering the overall objectives and implications.
 <b>5</b> <b>Planning</b>	Course of action or management plan.	Choose a course of action based on the information gained.	Choose an appropriate action based on the patient's values and preferences.	Solve the problem with doctors, caregivers and family.
 <b>6</b> <b>Management</b>	Patient adapts to the plan.	Patient decides on the management plan for adoption.	Discuss with doctors and/ caregivers about the management plan for adoption.	Eliminate uncertainty and adapt to the plan to achieve the objective.
 <b>7</b> <b>Follow-up</b>	Encourage patient to accept appropriate responsibility.	Follow the management plan.	Patients take responsibility for self-management to improve health and well-being.	Follow management planning to successfully meet the goals.

Table 7.1 shows the SRK based competencies for each information processing activity in the decision ladder. Each row in the table describes a single information processing activity and the column represent conceptualisation of behaviours that patients may exhibit when they perform an information processing activity. For example, a patient who has been diagnosed with CVD for more than 10 years would be demonstrating more skill-based behaviours, but may occasionally switch to rule-based behaviours.

### **7.3 Informal Expert Feedback**

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Cognitive work analysis modelling to support decision making was presented to researchers at the IBM, HP and Microsoft India. Human Computer Interaction researchers at the labs were contacted by email and phone to arrange a research meeting. A 40-minute presentation on CWA analysis and requirements were presented in each of the company labs to a total of 36 researchers (5 in IBM, 14 in Microsoft and 17 at HP) to gather feedback. Researchers were new to CWA so they wanted more explanation on the modelling process. This lead to refining this phase with more details for analysis. Researchers felt WDA and Decision ladder to be very useful for this study. As only CWA phase was presented researchers were not sure how the mapping in WDA was done. This lead to the formation of the descriptive theory and refinement of Chapter 6 – Theoretical Framework. Researchers were not sure how they could translate CWA analysis into software design and implementation. This feedback lead to the creation of Integration (Chapter 8) phase in CISDA.

## 7.4 Software Requirements Specification (Iteration 3)

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Chapter 5 (section 5.5) and Chapter 6 (section 6.7) help in documenting the Software Requirements Specification for the prototype development including: introduction to the decision aid, overall description, external interface requirements, and functional requirements. As decision making involves: different human actors, interaction with various resources, and various courses of action, it is essential to gain a systems-level view to understand the system features needed for the decision aid and non-functional requirements. The Software Requirements Specification is further updated in this phase using the IEEE Software Specifications Template (ANSI/IEEE Std. 830-1984).

*Table 7.2a: Software Requirements Specification – Performance Requirements*

Performance Requirements (Non-functional Requirements)	
Purpose: Identification of non-functional requirements also play an important role as the functional requirements.	
Competency support	Each and every person is different, hence 'one size fits all' does not work in all the situations. The system needs to support different abilities using the SRK Taxonomy as shown in Table 7.2. This competency analysis provides basic information needed for supporting requirements and knowledge for systems design and does not provide all the information needed for fully addressing human cognition.
High level Requirements	From the WDA analysis, the high level requirements for the system become obvious (Table 7.3).
Support for Normative and Rule-based Decision	The Decision Ladder and Strategy Analysis indicate that there are two types of decision requirements: the 'normative' sequence of stages through which one passes in order to make a decision and the decision 'shortcuts'. The 'normative' sequence is, in a sense, the rule-based approach in which patients comply with the instructions provided to them by health practitioners.

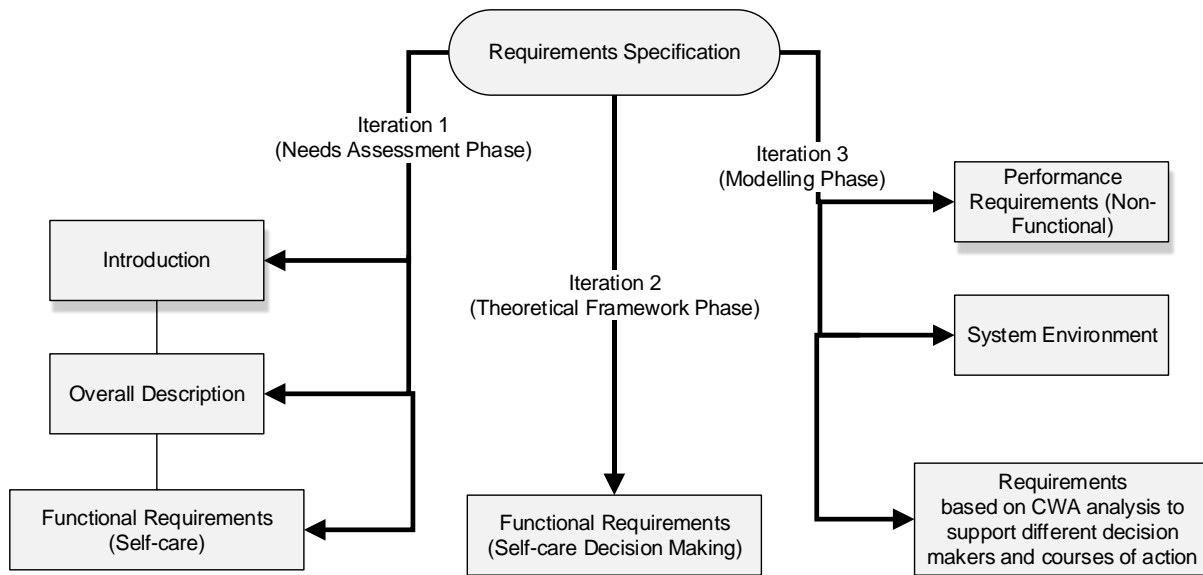
Table 7.2a shows the non-functional requirements such as performance requirements and Table 7.2 b shows the system features needed in the design of DA. Table 7.2c shows the requirements needed to support different types of decision making. Alternatively, one can look at the ‘shortcuts’ in which patients omit some of the steps in the Decision Ladder and ask how these might be considered in the design of DAs. In requirements Table 7.2c, these approaches lead to different designs. In each design, the emphasis is less on providing information or cueing particular decisions and more on helping the patient to either recall similar experiences or to offer a means of recording the decision being made (for later recall).

*Table 7.2b: Software Requirements Specification – System Environment*

Software Requirements Specification – System Environment	
Purpose: This section is part of the Overall Description in Chapter 5.5 to document the system features needed for the decision aid.	
System Feature 1 – Social and Organisational	Different actors/ stakeholder have different roles and tasks as shown in Figure 7.2.
System Feature 3 – Abstraction Decomposition Hierarchy	Figure 7.1: Abstraction hierarchy provides an ecological perspective of the work domain for coping with unanticipated and uncertain decisions. WDA provides information on the needs to be derived, means-ends and part whole relationships to understand the interactions between the functions, inputs and outputs that need to be designed in the system.
System Feature 3 – Abstraction Decomposition Hierarchy	The layout of the system into total system, components and sub-components is shown in Figure 7.2.
System Feature 4 – Strategies	The system should be built to support human cognition problems raised in section 2.6. The system should be capable of supporting various decision strategies and at the same time be flexible enough to allow patients to change between strategies effortlessly.
System Feature 5 – Decision Process	<p>CTA (Figure 7.4) identifies the requirements associated with known, recurring classes of situations needed for supporting different courses of actions in decision making depending on the decision problem, patient skills, rules and knowledge.</p> <p>Figure 7.4 shows the input-output, sequential flow of events and the timeline of events to identify the support needed for decision making. This also allows the designer to achieve flexibility in the design of the systems for supporting various decisions, and also helps to extend the cognitive abilities of the user, reduce user's information processing task by inducing expert actions for cognitive efficiency.</p> <p>Decision ladder provides a template for the designers to break down the decision process into its constituent states and knowledge for supporting information processing activities. In addition to that decision ladder provides information on lower order data and higher order information data or requirements for supporting the decision process.</p>

Table 7.2c: Software Requirements Specification from CWA

1. Requirements Based on AH Phases	
<b>Functional Purpose Values &amp; Priority Measures</b>	Design objectives: DA should be capable of guiding patients in their decision making process. DA should help patients to improve self-awareness, reduce risks, help in shared decision making and manage health information by recording everyday activities.
<b>Purpose-related Functions</b>	Provide clear paths—including initial steps—for the user goals. Based on the decision problem, DA should generate a schema and initial plan based on considering all the purpose-related functions through pattern matching, helping patients to recall from past experiences.
<b>Object-related Processes</b>	Patients need to make their own decision so the system should not force patients instead guide through the process. Provide clear information sent at choice points to guide users to their goals through diagnosis and options generation. Provide feedback and status information to show users their progress toward the goal. Allow users to back out of tasks that didn't take them toward their goal and record their progress.
<b>Physical Objects</b>	Store information about patient's medical history, medications, side-effects and other information based on AH.
2. Requirements Based on Strategies Analysis	
<b>Decision Problem</b>	Help patient to define the decision problem. For example, when the patient has a decision problem, the user should choose the decision problem as – ‘Pain’, or ‘Feeling Unwell’.
<b>Situation Assessment</b>	DA should help patients to identify the exact problem. Ask questions, help patients to recall their activities to find out if any lifestyle or behavioural or medication could have caused the problems. Help patient to apply past experiences in understanding the current decision problem.
<b>Diagnosis Options and Evaluation</b>	Summarize patients' identification of the problem and its cause for correct interpretation by looking into side-effects and medical history.
<b>Plan and management</b>	Help patients to evaluate the options from trusted information sources like American Heart Foundation, NHS (National Health Service, UK) and BHF leaflets.
<b>Follow-up</b>	Help in patients care plan and management.
<b>Collect and Distribute Data</b>	Follow-up procedures are created based on the care plan and management. Easy to use application to collect and store everyday activities
3. Requirements Based on Decision Ladder for Shortcuts	
<b>Schedule Visit GP/ Call Ambulance</b>	Help patients to schedule their diet, medication, exercise and follow-up meetings If the patient wants to see GP or call ambulance, DA should help patients.
<b>Wait and Watch</b>	DA should be able to record patients' decision making process along with the decision so it can follow up.
<b>Review Past Experience</b>	DA should be able to record all patients' decision needs and decision making process so that the system can help patient recognize past experiences and apply this knowledge in identifying and solving problem.
<b>Reminders</b>	DA should provide reminders for treatment adherence.



*Figure 7.5: Software Requirements Specification in Iteration 3*

A summary of the different software requirements extracted in three iterations (Chapter 5, 6 and 7) is shown in Figure 7.5. This shows that systems for supporting decision making need different levels of analysis to extract and to understand decision making.

## 7.5 Phase Summary

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This phase helps to address some of the complexities (section 2.1) and problems identified in section 2.6 by decomposing decision making through the multi-stage analytical framework for identifying the ‘system features’ and ‘performance requirements’ at several levels of abstraction and decomposition. It is proposed that the majority of contemporary patient DAs focus on specific problems in very high-risk areas or focus on giving the “right” answer to the patients. Some researchers focus on developing expert and decision support systems that code, filter, and interpret sensed data using algorithms based on heuristics and traditional biomedical models to detect and diagnose patient events; however, they are currently constrained by the limited capabilities of the programmed software and sensor technology

(Hajdukiewicz et al., 2001). Thus, commercial patient DAs might not support patients in their decision making processes but rather concentrate on the provision of information. In some instances, patients might need support and guidance more than information. It is proposed that the frameworks outlined in Table 7.2 could be used to survey these (and this is the subject of ongoing work).

This model supports even non experts with a comprehensive and systematic representation of the system and for catching potential problems, understand how systems interact with other agents and the information flows. This also helps to identify the means-end relations to examine the path between individual element and system goals. Thus this chapter shows how designers of DAs can gain several benefits from using CWA. This approach will contribute to the design of DAs for CVD patients in supporting patients' ability to make decisions as opposed to simply encouraging them to comply with rules. This approach is based on two basic assumptions.

## Chapter 8 PHASE IV INTEGRATION

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*You can design and create, and build the most wonderful place in the world. But it takes people to make the dream a reality - Walt Disney*

In the previous chapter CWA has proved successful in supporting the human factors analysis, and providing a systems-level view of operations. However, a critical gap exists in the transition from CWA to prototype design and implementation. This chapter starts with guidelines for the developers to help in the implementation process followed by a case study. The aim of this chapter is to fill this gap between CWA and implementation using Unified Modelling Language (UML) models. The approach presented in this chapter is intended to be minimalist and streamlined to focus on the design of a prototype. This thesis should provide a source of guidance for human computer interaction practitioners in developing systems from CWA without losing any information to build efficient systems.

### 8.1 Integration Phase Guidelines

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#### **Purpose**

This section provides guidelines for decision aid designers to carry out the integration phase derived from the CISDA process. This phase helps in bridging the gap between CWA and implementation of software specification.

#### **Thesis Composition**

This phases consists of:

- Study Background - provides background on the gaps in translating CWA to software specifications and design.



- CWA to UML - shows the steps involved in translating CWA to UML.
- Informal Expert Feedback - study presentation to experts to gather feedback on the translation process used.
- Phase Summary

## **Methods**

This phase uses UML for translating CWA for software design and implementation. This thesis does not specify UML as the only method for translating from CWA, it was found useful for this study. Other techniques that could be used is SysML.

## **Participants**

Presentation was done at Qualcomm Research Lab, Cambridge UK for HCI researchers. Five participated in the research presentation.

## **Outcomes**

Software design for implementation.

## **Quality Criteria**

1. Does the integration help in translating the modelling analysis into software specifications?
2. Is the process consistent from theory to integration?
3. Has all the modelling translated into software specifications?
4. Are the steps for translation well-defined and can it be re-engineered?

## **External Dependencies**

Validating the modelling approach with subject matter experts (optional).

## 8.2 Study Background

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Literature studies show that the primary means by which CWA leads to design is through Ecological Interface Design (EID) (Vicente and Rasmussen 1992; Burns and Hajdukiewicz 2013). In EID the user interface presents information relating to each level of the Abstraction Hierarchy (AH) (often, but not always, in separate regions of the screen) and particular emphasis is given to representing the relationship between the different constraints identified in the values and priorities level of the AH. Thus, the abstract function (values and priorities) would be reflected by the main parameters that the ‘system’ is using and the causal relations between these. Often EID is applied in process industries and so these variables tend to be mass, energy, flow or mass-balance designs. EID does not offer a systematic methodology or the rationale for decisions about mapping of constraints onto the visual forms (Mendoza, Angelelli & Lindgren, 2011; Upton and Doherty 2008; Jamieson and Vicente 2001). In particular, the use of mass-balance to show relations between AH’s values and priorities can lead to fixedness in EID with similar designs appearing in a variety of applications. In some of the applications it is a metaphor rather than a concrete representation.

Although CWA could be seen as a design method (Bisantz et al., 2003), there is lack of evidence to directly inform design. To address this challenge, a review of papers was carried out to understand how CWA analysis has been translated into software design and how the application has been developed. The review used IEEEExplore, Science Direct and PubMed database using “CWA” and “Cognitive Work Analysis” as the search term. One hundred and ninety-two documents were retrieved. Following abstract selection, full papers were reviewed. From this set, 14 papers were selected based on the interface design or prototype discussions.

*Table 8.1: Research on translating CWA to Interface Design and Evaluation*

Reference	CWA Stages	EID Used	Interface Shown	CWA to prototype
Dalinger and Ley (2011)	WDA	No	No	No
Monta et al (1992)	Work Domain Analysis	Yes	No	No
Bennett (2014)	Work Domain Analysis, Decision Ladder	Yes	Yes	No
Lintern (2006)	Work Domain Analysis, Abstraction Decomposition	No	Yes	Little info
Jenkins et al (2007)	Work Domain Analysis	No	Yes	No
Kuo and Burns (2000)	Work Domain Analysis	Yes	No	No
Monta et al (1992)	Work Domain Analysis	Yes	Yes	No
Cornelissen et al (2013)	Work Domain Analysis	No	Yes	No
Ellerbroek et al (2011)	Work Domain Analysis	No	Yes	Yes (Some Mathematical)
Dinadis and Vicente (1996)	Work Domain Analysis	Yes	Yes	Little info
Jamieson et al (2007)	Work Domain Analysis, Control Task Analysis	Yes	Yes	No
Groskamp et al (2005)	Work Domain Analysis, Control Task Analysis	Yes	Yes	No
Paradis et al (2005)	Work Domain Analysis	No	Yes	No
Gous (2013)	Work Domain Analysis, Control Task Analysis, Strategy Analysis, Social Organisational and Competencies Analysis, Worker Competency Analysis	No	Yes	No

In summary, analysing Table 8.1 studies show that CWA design concentrates on one or two of the five CWA phases, and only a small number of studies have attempted to use all the phases (Burns, Ho & Arrabito, 2011; Jenkins et al., 2011; Lintern, 2006; Naikar & Saunders, 2003; Van Dam, Mulder & van Paassen, 2008; Read et al 2012). There is little evidence of translating CWA to software design and implementation. Due to the lack of process or guidelines, translating CWA into design remains ambiguous, and more of an art than a science (Read et al 2012, Mendoza; Angeles & Lindgren, 2011; Jenkins et al., 2010, Lintern, 2005; Potter et al 2002; Bisantz et al 2003). Although the studies have shown screenshots of their interface, it is not clear how CWA has been applied to these designs (Read et al 2012; Jamieson et al 2007; Naikar 2006; Bisantz et al 2003; Jamieson and Vicente 2001; Watson and Sanderson 2007; Euerby et al 2012). EID does not offer a systematic methodology or

reveal the rationale for decisions on mapping the constraints onto the visual forms (Mendoza, Angelelli & Lindgren, 2011, Upton and Doherty 2008, Jamieson and Vicente 2001).

It is clear that there are gaps in the application of CWA to design and a clear challenge lies in clarifying approaches to human–system interface requirements (Bisantz et al 2003). As the goal of CWA is to apply knowledge of human activities to design to improve system performance, it is vital that CWA goes beyond analysis to support design (Read et al 2012). Application of human factors for systems engineering and software design imposes the need for translating human elements into software specification for design, development and testing (Booher 2003).

### **8.3 CWA to UML**

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This translation from CWA to UML was carried out using the following UML diagrams:

- Use case diagrams: for mapping the functional requirements or user needs for the system.
- Class Diagrams: to understand what classes are needed, their relationships, attributes and operations. It is similar to the domain model in systems engineering.
- Package Diagrams: for grouping classes and interfaces
- Sequence Diagram: is used to specify the type and order of messages passed between elements during execution.
- State diagrams: is used to describe system states and transitions to be triggered for state changes.

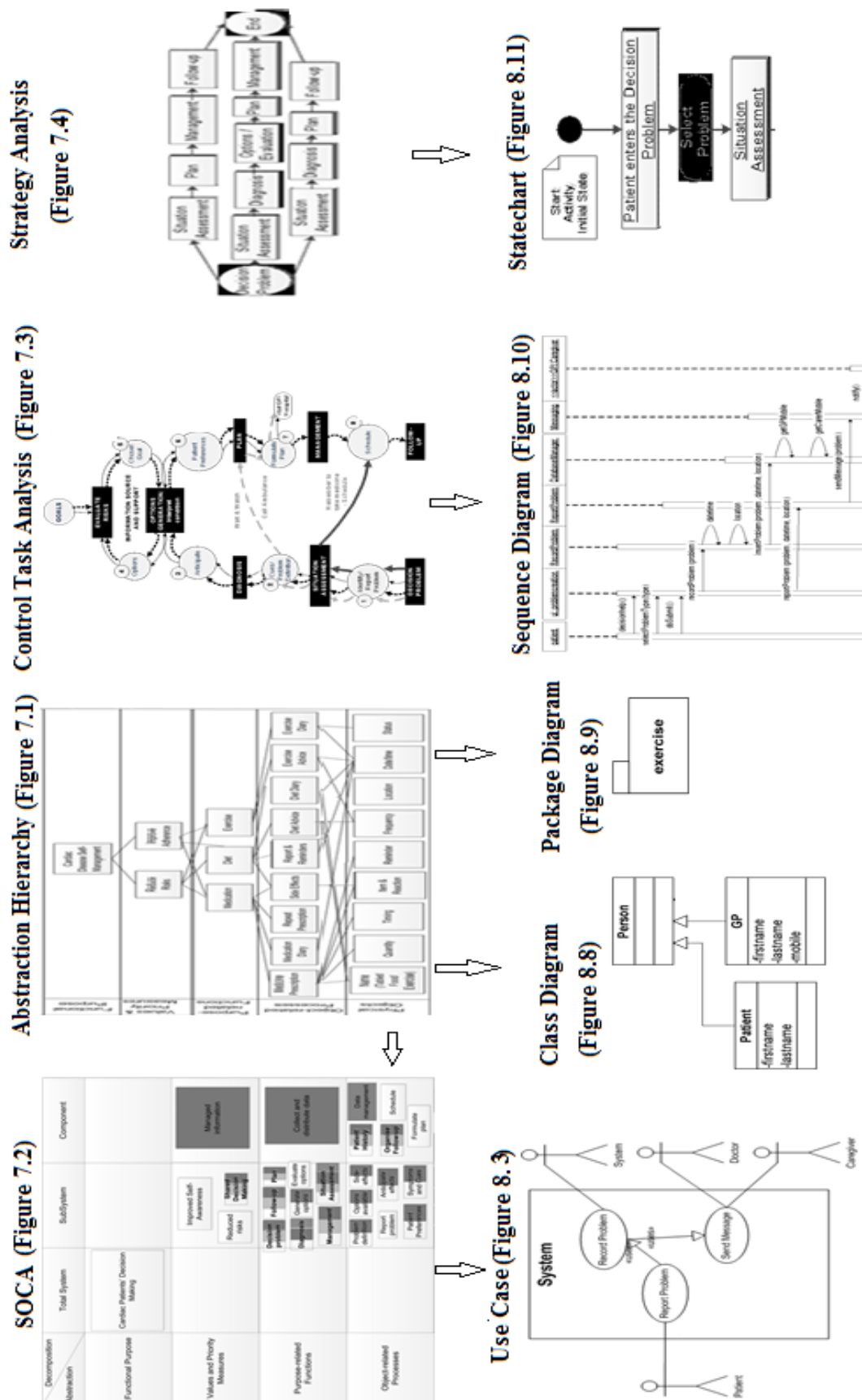


Figure 8.1: Study Approach from CWA to Prototyping using UML

Figure 8.1 provides an overview of the integration approach undertaken in this study to make sure that there is some consistency in the approach. It is believed that this approach should be minimal yet sufficient to capture CWA analysis for coding efficient systems. For illustrative purposes, in this chapter, the design process results in an app running on a smartphone.

### 8.3.1 Use Case Modelling from WDA and SOCA

Use case diagrams provide an overview of the system functionality and scope by providing a visual representation of the relationships between the individual use cases and the primary and secondary actors (Eriksson et al., 2008).

#### Objective

Using WDA and SOCA the functional requirements are mapped to understand the needs of the system as use cases.

*Table 8.2: Use Case Diagram Creation*

Information for construction	CWA Diagrams
<b>1. Actors</b> Identify groups of actors and their use of system	<b>AH and SOCA</b> Stakeholders (actors) are identified and description of how they will use the system is derived from WDA and SOCA
<b>2. Identify Cases</b> The use case required for the system	<b>AH</b> AH “Purpose-related functions” to identify the use cases for the system
<b>3. Actions</b> Identify clear set of jobs for the system	<b>AH</b> AH mappings between “Object-related Functions” account in “Purpose-related functions”
<b>4. Relationships</b> Define the relationships like <<include>> and <<extends>>	<b>AH</b> Based on the overlaps in the mapping between “Object-related Functions” and “Object-related processes” also there are some overlaps in the mapping between “Object-related processes” and “Physical Process”

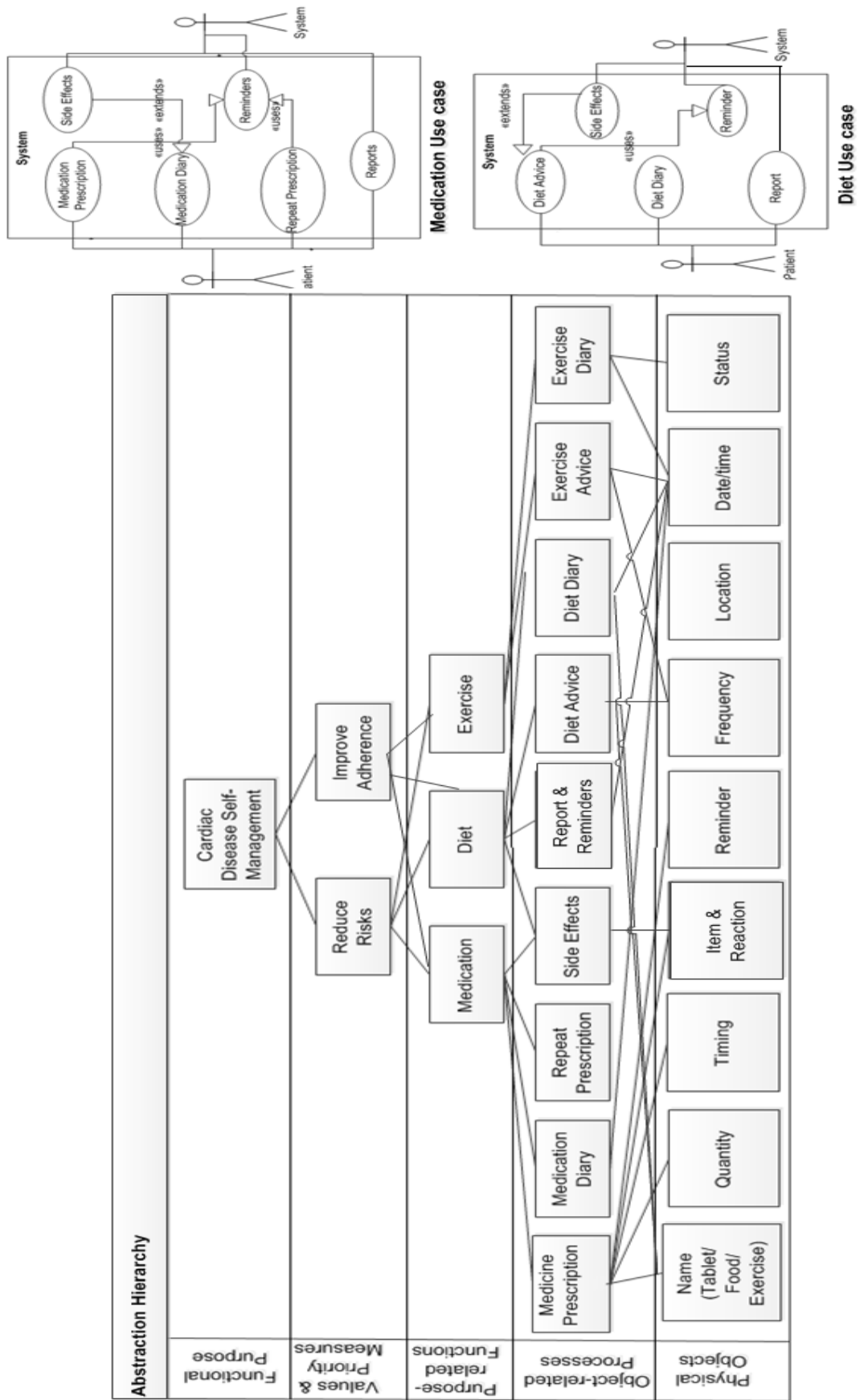


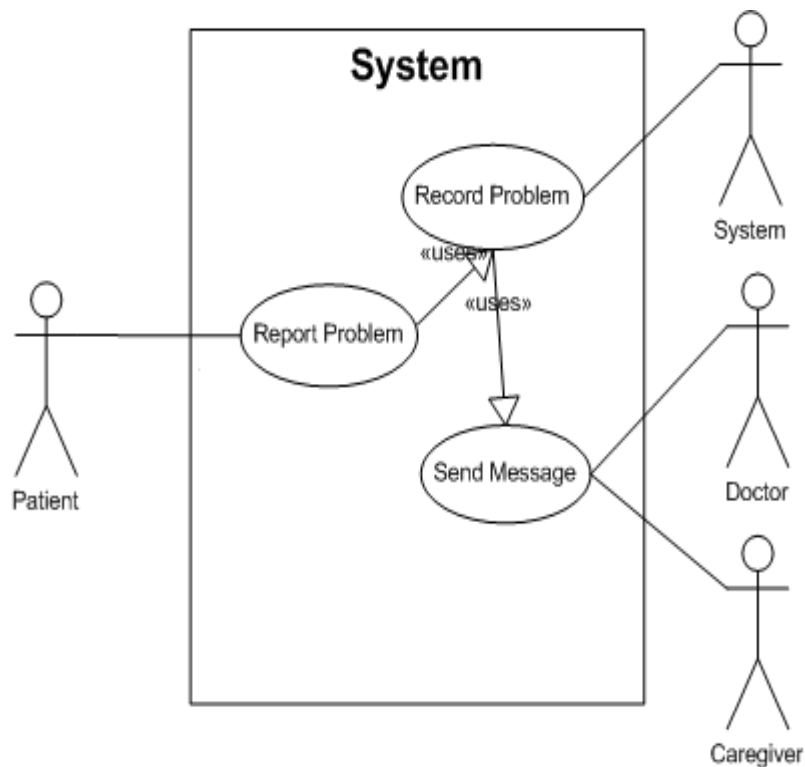
Figure 8.2: AH and its Use Case showing the Steps

## Process

Table 8.2 shows the steps involved in the creation of use case using:

1. **Identify Actors:** Identify the stakeholders (actors in UML terms) or the “thing” (probably not a user, maybe some control or system) interacting with the system derived from WDA and SOCA (Chapter 7 Figures 7.1 – 7.3) i.e., patients, doctors, nurses, and caregivers.
2. **Identify Cases:** Use AH “purpose-related functions” to identify the use cases for the system, e.g., “Medication, Diet, Exercise and Schedule” as shown in Figure 8.2. Please note the AH diagram in Figure 8.2 is constructed the same way as described in Chapter 7 to support self-management.
3. **Actions:** Identify system operations using AH mappings between “object-related functions” account in “purpose-related functions”. The operation might be to allow the user to enter a record. For example, Figure 8.3 shows the use case for the decision problem.
4. **Relationships:** Use cases also define the relationships like <<include>> (to represent reusable part of the system) and <<extends>> (where reuse is optional). Some relationships can also be derived based on the overlaps in the mapping between “object-related functions” and “object-related processes” and by considering the mapping between “object-related processes” and “physical objects”. For example, medication in Figure 8.2 shows that “side-effects” and “reminder” are linked with “medication and diet” hence these can be classified as reusable parts of the system. Moreover, “side-effects” can be optional as there may or may not be some side effects linked with a particular diet and/ medication.





*Figure 8.3: Decision Problem Use Case*

### 8.3.2 Class Diagrams Using AH

Class diagrams are used to describe the characteristics of different types of objects that the system can have, along with their relationships. Using AH class objects can be created. The main challenge in OOP is in identifying the classes and their relationships. This process represents some of the most important concepts in object-oriented design and, when applied correctly, can help in the creation of reusable design.

#### Objective

As AH allows the analyst to decompose the system from general functions to its physical form, this information can be used to derive classes required for implementation. This section

describes the process for creating class diagrams and their relationships from AH. In particular, this approach works from the “Values and Priorities” in the Abstraction Hierarchy. This echoes the approach in EID, in which these processes are reflected in mass-balance diagrams. However, by proposing the description in terms of Class Diagram offers an opportunity to consider alternative representations rather than simply opting for the mass-balance format and seeking to fit the relationships into that diagram.

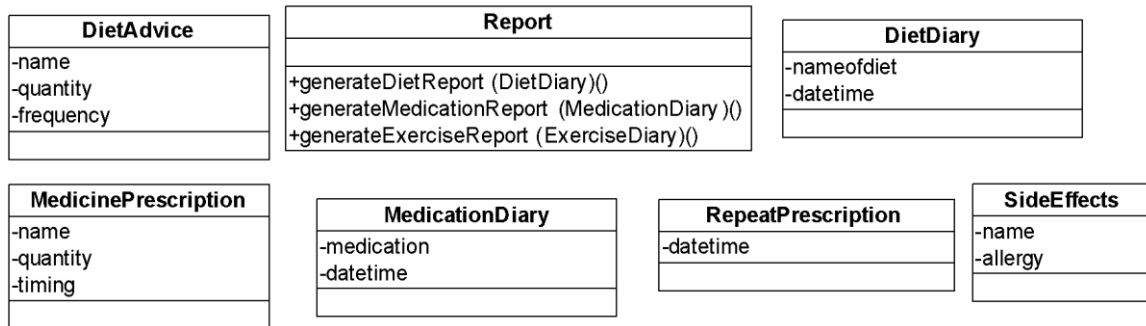
*Table 8.3: Class Diagram Creation*

Information for construction	CWA
<b>1. Identify Classes</b> Identify the classes required	<b>AH</b> AH’s “Object-related processes”
<b>2. Identify Attributes</b> The characteristics required for the class.	<b>AH</b> Based on the mappings between “Object-related processes” and “Physical Objects”.
<b>3. Operations</b> The functions required by the class.	<b>AH</b> Based on some “Physical Objects”
<b>4. Class Relationships</b> Identify the relationships between the classes	<b>AH</b> AH does give some indication on the relationships between the classes but it is up to the designer to specify the exact relationship needed.

## Process

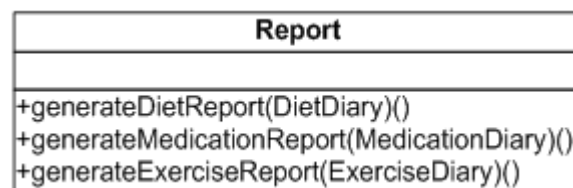
Table 8.3 is designed to help in the creation of class diagrams using the following steps:

1. **Identify Classes:** Identify the classes required from AH’s “Object-related processes”.  
Some of the classes identified based on the AH Figure 8.2 is shown in Figure 8.4 like DietAdvice, Report and DietDiary classes.
2. **Identify Attributes:** Identify the attributes required based on the mappings between “Object-related processes” and “Physical Objects”. For example, the attributes (name, quantity, frequency) for each of the classes in Figure 8.4 derived from AH Figure 8.2 is shown below.



*Figure 8.4: Class Diagram*

3. Operations: As AH deals with high-level view of the system, it does not dwell into the finer details required for development except some guidelines. For example, some of the “physical objects” refer to operations required to carry out certain functions like “Report” class has “generateDietReport for Diet as shown in Figure 8.5.



*Figure 8.5: Reports Class Diagram*

4. Class Relationships: UML offers five different types of class relationships: dependency, association, aggregation, composition and inheritance. AH does give some indication on the relationships between the classes but it is up to the designer to specify the relationship as shown below. Relationships can be derived based on the overlaps in the mappings between “Object-related processes” and “Physical Objects” as shown in Figures 8.6 – 8.8.

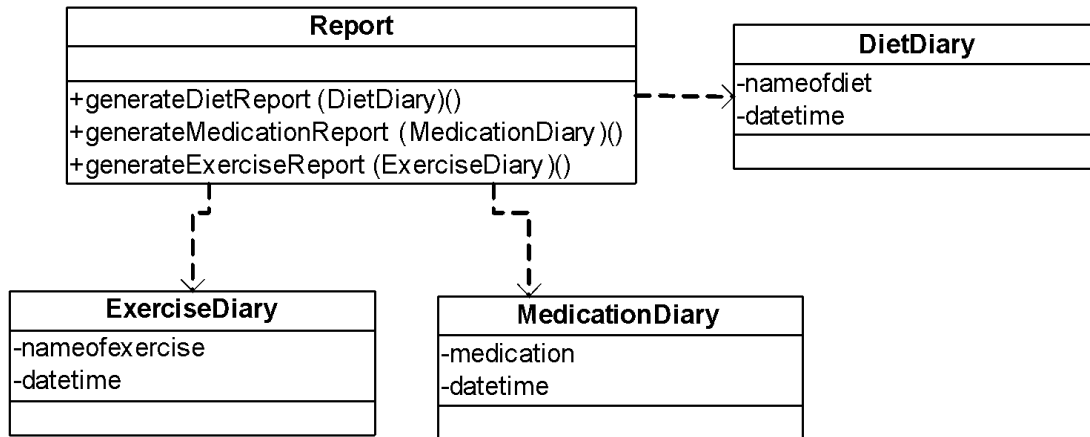


Figure 8.6: Report is dependent on other classes



Figure 8.7: The Patient class is optionally associated with zero or more objects of the Allergies class; The Allergies class is also associated with one and only one Patient

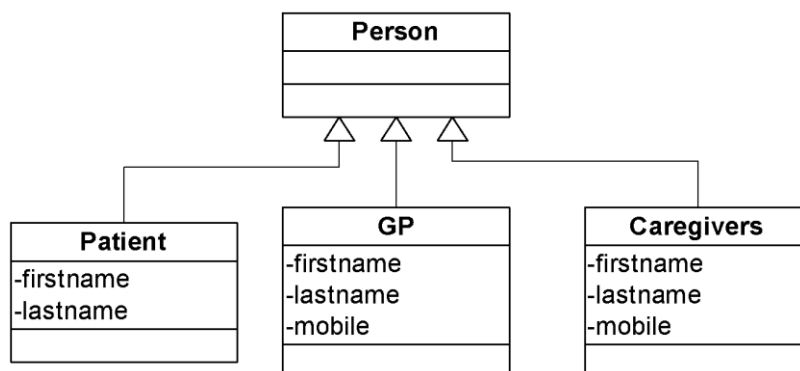


Figure 8.8: Inheritance or generalization can also be identified based on AH mappings in the bottom three stages. Here Patient, GP and Caregivers are type of Person

### 8.3.3 Packages Using AH

Package diagrams allow designers to easily organise classes into packages without much research intrusion.

#### Objective

This section specifies how to group classes in UML packages using AH.

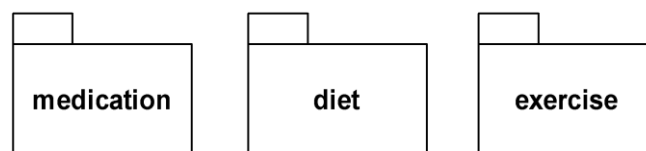
*Table 8.4: Package Creation*

Information for construction	CWA
<b>1. Identify Packages</b> Identify the packages required	<b>AH</b> AH's "Purpose-related functions"
<b>2. Identify Class Groups</b> Organise classes into logically related groups.	<b>AH</b> AH mappings between "Purpose-related functions" and "Object-related processes" to group the classes

#### Process

Table 8.4 helps in the creation of UML packages using the following steps:

1. Identify Packages: Identify the packages required from AH's "Purpose-related functions". Figure 8.9 shows some of the packages derived from AHs. Although packages can be derived from AH analysis, it is up to the software designer to make their own design decisions depending on the relationships and the number of classes used to carry out a particular goal. For example, planning and management in AH can be combined into a single package for the prototype.



*Figure 8.9: Packages based on all the AH*

2. Identify class groups: Based on the AH mappings between “Purpose-related functions” and “Object-related processes” the classes are grouped in the packages. For example, medication related classes are grouped under “Medication” in purpose-related functions. Although “side effects” is linked to Medication it is also associated with other classes hence it is decided to keep it separate like a utility package.

### 8.3.4 Sequence Diagram using Decision Ladder

Sequence diagrams show which objects are responsible to carry out the functions in the code and how the messages are communicated between the objects, thus giving a behavioural representation. Sequence diagrams can get easily clustered with too many messages and can become difficult to understand. By starting from a higher level with decision ladder this approach will help the designer to focus on separating the sequence diagrams based on the data processing required hence allowing the designer to dwell into the details required for each segment. Also, many designers struggle to apply sequence diagrams appropriately, this approach should help designers.

*Table 8.5: Sequence Diagram Creation*

Information for construction	CWA
<b>1. Identify Actors</b> Identify the actors that interact with the system	<b>AH/ Use Case</b> Use cases derived from AH shows the users of the system
<b>2. Identify user interface fragment</b> User interface to help in user interaction.	<b>Decision Ladder</b> Look at decision ladder “Data processing”
<b>3. Identify Fragments</b> Fragments are represented as a box to enclose the interactive portions	<b>Decision Ladder</b> By looking at the decision ladder’s “State of Knowledge” and its use case diagrams
<b>4. Identify Database Interactions</b> This fragment is optional depending on the requirement	<b>AH/ Use case</b> Shows the interaction of the system

## **Objective**

A Decision ladder shows the information flow in the decision making process while the sequence diagram shows the objects and their operations involved in achieving the goal. The decision ladder involves many steps, and putting these into a single sequence diagram could make it complicated. As CWA has provided end-to-end decision process, during modelling, it makes more sense to look into sections of the decision making process. This section specifies how to create sequence diagrams.

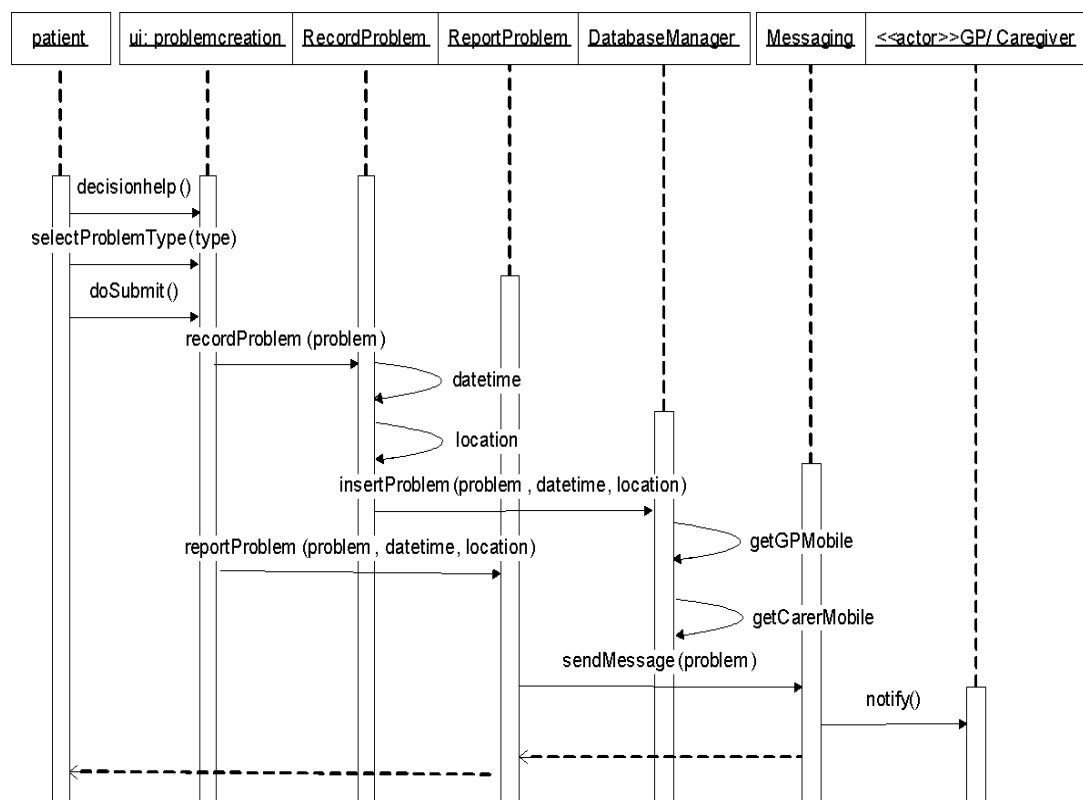
## **Process**

To develop sequence diagrams, each of the “Data processing activities” and its resulting “State of knowledge” as shown in Chapter 8 (Figure 7.4) are used. As “State of Knowledge” refers to the relevant AH “Object-related processes”, this section uses decision ladder along with use cases for the creation of sequence diagrams. Moreover, as there is some overlap (shown in Figure 8.10) in “Options and Evaluation” it can be combined into one sequence diagram if necessary. Table 8.5 helps in the creation of sequence diagrams using the following steps:

1. **Identify Actors:** Identify the actors that interact with the system using use case diagram for the given decision ladder data processing section as shown in the use case section.
2. **Identify user interface fragment:** Using the decision ladder “Data processing” sections, the sequence diagram for “decision problem” is developed. The user interface should help the patient in “problem creation” as shown in Figure 8.10.
3. **Identify Fragments:** Fragments are represented as a box to enclose the interactive portions. A sequence diagram can contain any number of fragments as shown in

Figure 8.10 as long rectangles. By looking at the decision ladder’s “State of Knowledge” and its use case diagrams it is easy to implement the fragments needed for sequence diagrams.

4. Identify the database interactions: This fragment is optional depending on the requirement. If the systems in the use case refer to databases then using this fragment shows how the processed data are stored. For example, Figure 8.10 shows how decision problems are stored in the DatabaseManager.



*Figure 8.10: Sequence Diagram for Decision Problem*

### 8.3.5 Strategies Analysis and Activity Diagram

Activity diagrams are used for modelling the system workflows, that is to specify how the system will accomplish the goals rather than specifying details about the operations and



messages. Using high-level view of Strategies Analysis, activity diagrams help to better visualize the steps involved for implementation especially the branching steps that could not be achieved without Strategies Analysis.

## Objective

To show how to create activity diagrams based on Strategies Analysis.

*Table 8.6: Activity Diagram Creation*

Information for construction	CWA
<b>1. Initial and final nodes</b> Represents the start and end of the activity	<b>Strategies Analysis</b> This is derived using the start and end of Strategies analysis course of action
<b>2. Object Nodes</b> Represents the flow of data through an activity.	<b>Strategies Analysis</b> Identified using the steps involved in each course of action
<b>3. Actions</b> Important steps that take place in the activity	<b>AH</b> Looking at the AH mappings for the object nodes

## Process

Activity diagrams can be created using the various courses of actions as shown in Strategies Analysis. Table 8.6 helps in the creation of activity diagrams using the following steps:

1. Initial and final nodes: represents the start and end of activity. This is derived using the start and end of Strategies analysis course of action.
2. Object Nodes: to represent the flow of data through an activity. Object nodes can be identified using Strategies Analysis as shown in Figure 8.11.
3. Actions: are the important steps that take place in the activity. These actions can either be derived from use cases or by easily looking at the AH mappings for the object nodes.

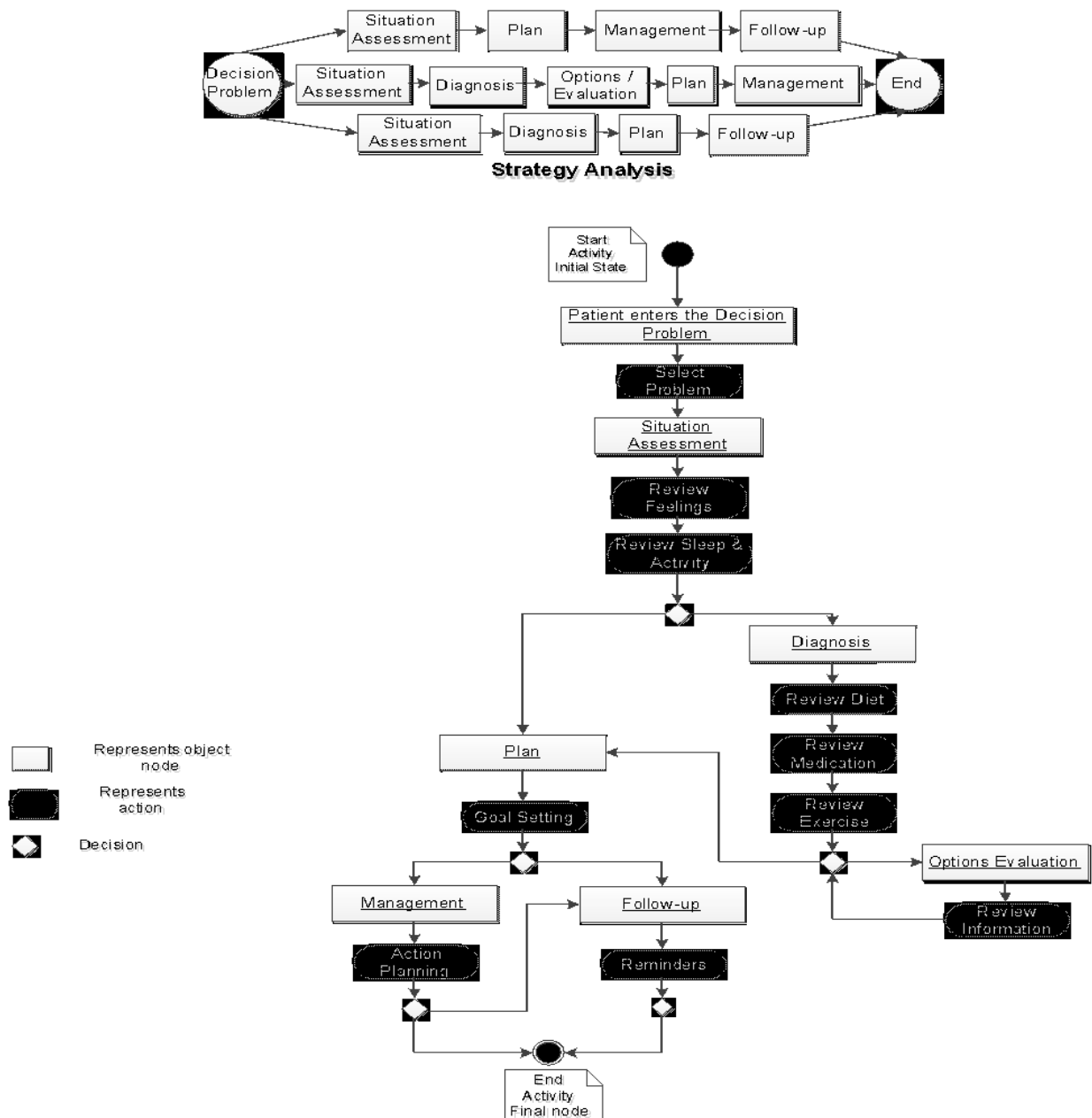


Figure 8.11: Strategies Analysis to Activity Diagrams

## 8.4 Informal Expert Feedback

Like the presentation of the modelling phase (Chapter 7) to researchers at IBM, HP and Microsoft India, this phase was presented to the human computer interaction (HCI) researchers at the Qualcomm lab. Researchers in the field of HCI were contacted by email

and phone to arrange a research meeting. A 40-minute presentation on the translation of CWA analysis into UML was presented to 5 researchers. The following feedback helped to refine the CISDA process and translation:

- The researchers felt that a step-by-step process would help in the translation of CWA to UML. This phase was refined based on the feedback to include templates and representation of mappings.
- Researchers wanted to see if there was a real gap in the research in translating CWA to software specifications. Section 8.2 is added to provide background details on the research.

## **8.5 Phase Summary**

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Although CWA analysis appears to have a growing interest in medical informatics for developing innovative training programs and human-computer displays, the studies does not provide any specific human-computer display designs (Hajdukiewicz et al., 2001). This phase addresses this issue by translating the requirements captured by CWA analysis from sections 5.5 and 6.7 into software specifications for the design and development of the prototype using step-by-step description. The approach provides us with several advantages:

- CWA analysis helps us to examine and replicate the actions of the stakeholders involved in the system, who are affected by the constraints outside the stakeholder's control.

- By understanding the constraints that shape the behaviour, the actor's environment, the ecology in which the activities take place and task, helps us to produce a better interface.
- Abstraction hierarchy and work domain analysis provide insights into the nature of functional interactions and partitioning of the functional complexity of the work domains for an in-depth analysis.
- Decision ladder and strategies analysis helps to figure out various approaches to support decision makers based on user's skills, rules and knowledge.
- User interface design remains grounded in an understanding of stakeholder roles, work domain and the requirements.

CWA helps shift the focus from the individual user *per se* to the system in which activity occurs. This offers the potential to capture the richness of the domain in ways that focusing design on the user's tasks and goals could miss. Moreover, the use of UML provides a broad system 'objects' in the software. The benefit of this approach (in comparison with EID) is that the relations between objects are not assumed to follow the mass-energy balance but could have other relations.

## Chapter 9 PHASE V INTERFACE DESIGN

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*"The teacher, if indeed wise, does not bid you to enter the house of their wisdom, but leads you to the threshold of your own mind." Khali Gibran (1883 - 1931), Lebanese American Artist, Poet, and Writer*

This phase deals with the design of a mobile interface for supporting self-care decision making through an iterative process. This chapter starts with guidelines for the developers to help in the implementation process followed by a case study. This phase also highlights some of the interaction models, styles along with prototype implementation.

### 9.1 Interface Design and Development Phase Guidelines

---

#### **Purpose**

This section provides guidelines for decision aid designers to carry out the interface design and development phase derived from the CISDA process. The aim of this phase is to provide an easy to use interface for people to interact with the system and implement the design using an incremental development process.

#### **Thesis Composition**

This phase consists of:

- Design Elements: highlights the design decisions using a mock-up based on CWA and UML models.
- Interface Design Process: design and evaluate iterative process.
- Design Evolution: highlights an evolution of the design using iterative process.

- **Prototype Implementation:** gives a brief overview on the implementation of the mobile prototype.
- **Phase Summary:** provides a summary of this phase.

## **Methods**

This phase uses an iterative approach for the design of user interface using various human computer interaction techniques.

## **Participants**

Patients diagnosed with CVD disease.

## **Outcomes**

User interface designed based on user's feedback to achieve usability.

## **Quality Criteria**

1. Are the screens or interface consistent with the modelling and integration analysis?
2. Are exit points explicit?
3. Are screens correctly used to present the probabilities in the context of the navigation specified?
4. Has navigation been minimized?
5. Is the overall design simple and flexible?
6. Does the design use plain language as specified in IPDAS?
7. How well does the design support user needs and mental models?
8. Can the user interpret what the representations used in the screen means easily and correctly?
9. Does the design satisfy usability requirements?
10. Has the user interface evaluated with the end users?

11. Does the prototype confirm the use of user interface elements?

## 9.2 Design Elements

---

The design of interface for self-care decision making is based on CWA analysis in Chapter 7 and UML diagrams in Chapter 8. Wireframes were used for the page layout. Interface contents for the screens are derived based on the following steps:

- i. Main screen (Figure 9.1 A): the user is presented with the main screen based on the use cases identified using the AH's purpose-related functions like 'diet', 'medication' and 'exercise'. In situations where there may be too many objects on the screen, it is assumed that the set of purpose-related functions might be split across several windows.
- ii. Sub-Menus (Figure 9.2 B): based on the AH analysis each main menus is linked with one or more object-related processes identified as sub-menus based on the use cases.
- iii. Page contents (Figure C): are derived based on the interactions of physical objects with the object-related processes in AH.
- iv. Decision Process (Figure D): based on strategies analysis the UML Activity diagrams (8.16) show the decision points and the navigation needed for interface design.

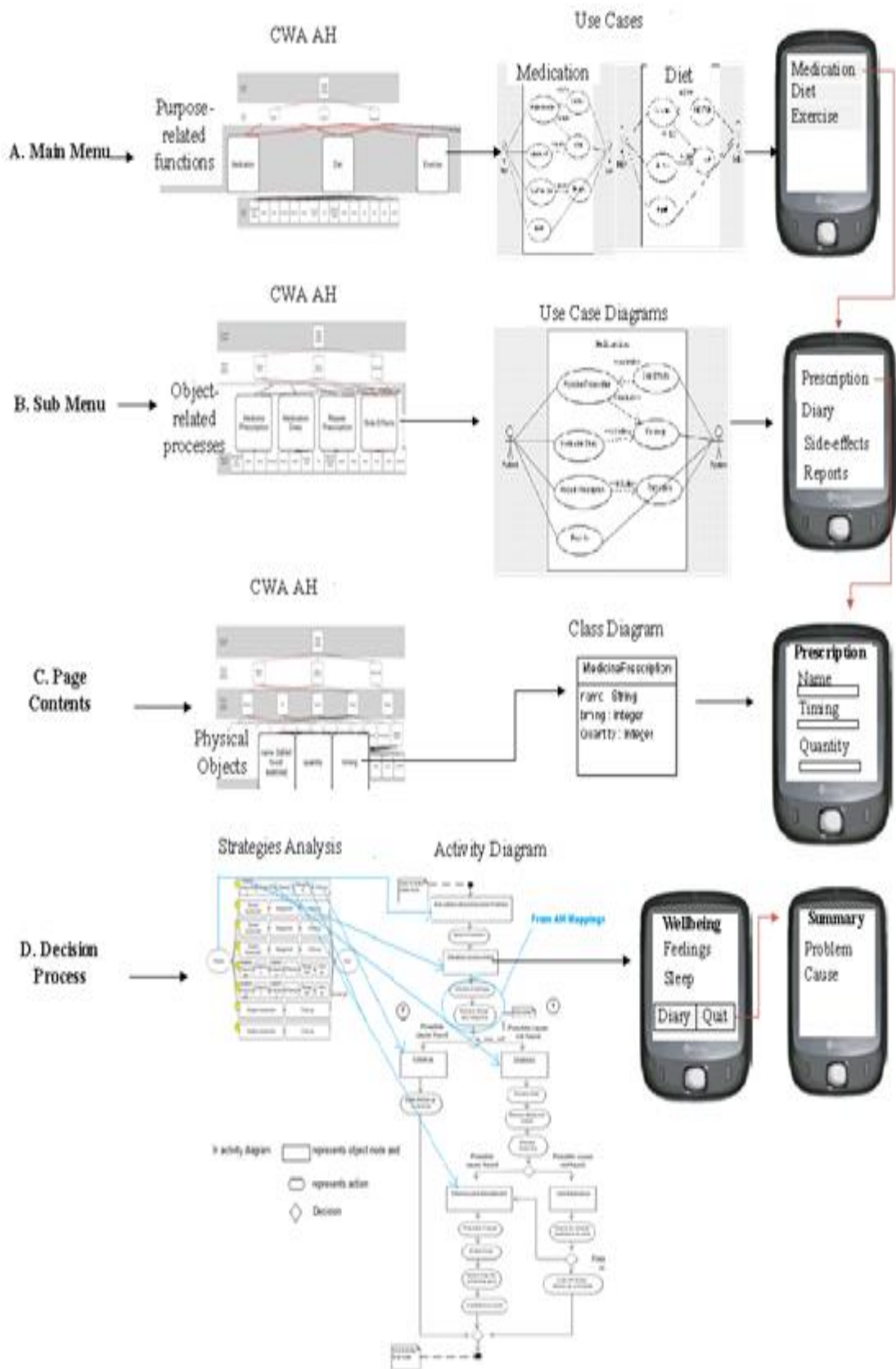


Figure 9.1: Overview for identifying screen contents using a mock-up (not a real design)



### 9.3 Interface Design Process

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Although the focus is not on the end product, this section provides guidelines to help in the design of interface using an iterative process (Figure 9.2).

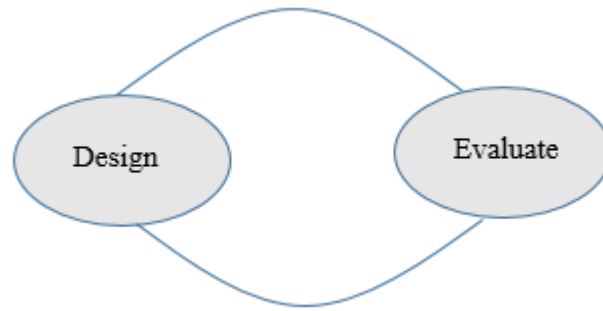


Figure 9.2: Iterative Interface design process

Based on the design highlights shown in previous section the initial prototype interface was developed as shown in Table 9.1. Table 9.1 shows the CWA AH phases along with the UML model and the design features. Two screen designs (I and II) are shown to show the initial designs and the revised designs after redesign and user feedback. Table 9.1 shows the evolution of the user interface after iterations carried out in two parts:

- a) Mobile Design: design of the mobile interface is carried out to using guidelines and user feedback.
- b) Evaluate (User Perception): focus group study and questionnaire study as shown in section 9.4.1 were carried out to understand user perceptions.

### 9.3.1 Mobile Design

There are lots of standards governing medical devices and many of these standards address user interface design – e.g., ISO 62366 is pretty comprehensive and covers all of the design features that need to be considered for increasing the systems usability. This section provides an overview of some of the design models, styles and motivation features that have been used in this chapter.

#### 9.3.1.1 Interaction Models

Some of the most commonly used models for example Normans' execution evaluation cycle for designing the users' view of interaction and Abowd and Beale's (1991) interaction framework are considered (Dix 2004).

The patient's decision making framework in Chapter 6 (Table 6.8) and CWA (Chapter 7) have given us detailed analysis of the decision making process. So using Normans' model (1988), high-level interaction for decision making is as follows:

**Goal:** (the decision problem; Chapter 6; Table 6.8) provide clear paths—including initial steps—for the user goals. For example, when the patient has a decision problem, the user should choose the decision problem as – 'Pain', or 'Feeling Unwell'.

**Execute:** should be based on the CWA strategies analysis and situation assessment (Chapter 6; Table 6.8) including – looking into patients' feelings, sleep pattern, diet intake, medication and exercise. Patients need to make their own decision so the system should not force patients, instead guide through the process. Warn users if they choose actions that seem to take them away from their goal in order to achieve it.

**Evaluate:** (evaluation; Chapter 6; Table 6.7) Provide feedback and status information to show users their progress toward the goal. Allow users to back out of tasks that did not take them toward their goal and record their progress.

### ***9.3.1.2 Interaction Styles***

Some of the interaction styles that were followed considering the patient population in this thesis are as follows:

- Consistency – screens need to be consistent throughout so patients have the same experience.
- Colours – due to mobile phone limitations on colour and visual deficiency in distinguishing the colours, usage of colours need to be minimal.
- Organise – arrange and group menus based on AH. Organise buttons into groups that make more sense.

### ***9.3.1.3 Motivation in Design***

Due to the age of the population and rate of technology adoption, patients must be motivated to use the system. For example, use techniques like (Torning and Oinas-Kukkonen 2009):

- Reduction: reduce complex behavior into simple tasks to help users perform the target behavior.
- Tunneling: guide users through a process or provide opportunities to persuade along the way.
- Tailoring: develop systems that are more persuasive by tailoring it to the potential needs, interests, and personality or user context.

Although theories from Positive psychology such as Cognitive Behavioural Therapy, Behaviour Change Support Systems, and Behaviour models have been promising for the study of user intentions and behaviour change. These theories like behaviour modification and the ways in which behavioural / psychological interventions are designed with the help of above techniques aid in behaviour change.

### 9.3.2 Evaluate (User Perception)

In this section, evaluates the interface design with the users.

#### 9.3.2.1 Method and Participants

A questionnaire study was conducted with 20 patients who were willing to participate in this study. The session was conducted as stated in section 4.4 (Chapter 4). Participants were in the age range of 50-89 and were conducted using BHF.

#### 9.3.2.2 Data Collection

This study used questionnaire to collect data. The questionnaire used questions similar to TAM (section 4.4).

#### 9.3.2.3 Analysis and Results

The questionnaire data were analysed using percentages as shown in Table 9.1.

*Table 9.1: Comparison between Users Perceived and Actual Use*

Questions	Feedback N=20
1. Easier for me to contact the physician.	15 (75%)
2. Can improve my general health.	9 (45%)
3. Useful for managing my health.	13 (65%)
4. I intend to use it/ adopt.	15 (75%)
5. Learning to use At-home healthcare system would be easy for me.	13 (65%)
6. Would be able to use without any help?	14 (70%)
7. Can violate privacy/ trust (data stored securely).	14 (70%)

#### 9.3.2.4 Summary

Although participants' intentions to use were positive, they raised some issues on the interface design as follows:

- Participants felt that there were too many clicks and it would not be possible for them to do every day.
- Participants were not comfortable typing in their food or selecting it due to some manual dexterity.
- Felt hard to read the text and icons were not very clear in the main screen.

The mobile phone interface is redesigned to overcome the above issues using an iterative process. This study has helped us to gain users perspective and issues on the design of the mobile prototype.

## 9.4 Design Evolution








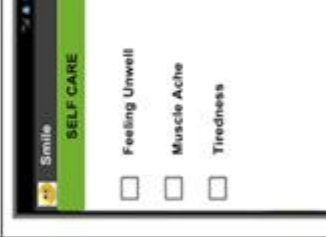

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Using the iterative design and evaluation as suggested in Figure 9.2 helps to refine and develop a better interface to meet user's needs and requirements and to achieve usability. Table 9.2 provides an overview of the iterations and the evolution of the interface design. Table 9.2 shows the CWA analysis along with the UML diagrams used in the screen design. The evolution of the designs are shown using two studies (Study I and Study II).

Study I - Features I specifies the design elements and the interaction styles used in the design. For example: control panel uses images and text (Features I, Main Screen).

Study II - User's Feedback (Evaluation) on Screen Design I is shown in Table 9.2. Features (II) for the design are refined based on the feedback. User interface is redesigned as shown in Screen Design II. Appendix I - shows the various designs used in gaining user perceptions and feedback. This shows that iterative process helps to develop better user interfaces that are usable and easy to navigate.

Table 9.2: Iterative Evolution of Interface Design

	Main Screen/ Home Page	Sub Menus	Input Page (e.g Diet)	Decision Support Pages (e.g. Diet)
CWA	Purpose-related Functions	Object-related Processes	Physical Objects	AH Mappings
UML	Use Cases	Use Case Diagrams	Class Diagrams	State chart
<b>STUDY I</b>				
Features I	Control Panel (with images and text)	List with text	Text box and drop down box	Large Text, scroll bars
Screen Design I				
<b>STUDY II</b>				
Users' Feedback	Icons not clear	Text not readable	Input of text is not easy	Navigation Problems - too many clicks
Features II	Control Panel (with images and text) and use pictures to represent the wellbeing data using emotions	Instead of using text, wherever possible images need to be displayed for point and click.	Take pictures or video	Tunnelling for user experiences in decision making by removing all the unnecessary functionality and by guiding user in decision making.
Screen Design II				
				

## 9.5 Prototype Implementation

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Evaluation is mainly carried out using mobile app demonstration and paper prototype as it was not possible to implement the app in user's phone. Therefore, a brief overview of prototype implementation is provided here to highlight the mobile application prototype. The prototype implementation was carried out using Android 4.1.2, Eclipse 3.7.2, and SQLite for mobile phone database to store the records. The database for the mobile app was created using SQLite browser. The tables for storing the data were extracted from the AH analysis (Chapter 8) for compliance and decision making. As described in the Class diagrams, it was necessary for classes like Patient, Allergies to just specify the required attributes and have two new classes for each of the main classes with suffix as "AddEdit" and "View" as shown in figure 9.3. The main app was named as "MyCarer", so the root package is "com.android.mycarer"

<pre>package com.android.mycarer.account;  import android.app.Activity;  public class AllergiesAddEdit extends Activity {     private DataBaseManager dataBase;      private int rowID;     private EditText _item;     private EditText _reaction;     /** Called when the activity is first created. */     @Override     public void onCreate(Bundle savedInstanceState) {         super.onCreate(savedInstanceState);         setContentView(R.layout.allergyaddedit);          _item = (EditText) findViewById(R.id._item);         _reaction = (EditText) findViewById(R.id._reaction);          Bundle extras = getIntent().getExtras();          if (extras != null) {             rowID = extras.getInt(ID);             _item.setText(extras.getString(ITEM));             _reaction.setText(extras.getString(REACTION));         }     } }</pre>	<pre>package com.android.mycarer.account;  import android.app.Activity;  public class AllergiesView extends Activity {     private DataBaseManager dataBase1;      private TextView textView;     private TextView item_text;     private TextView reaction_text;     private int rowID;     private int patientID;     private int _id;      private Cursor cursornew;      /** Called when the activity is first created. */     @Override     public void onCreate(Bundle savedInstanceState) {         super.onCreate(savedInstanceState);         //creates and open the database so we can use it         dataBase1 = DataBaseManager.instance();         Bundle extras = getIntent().getExtras();          setContentView(R.layout.allergyaddedit);          if (extras != null) {             rowID = extras.getInt(ID);             patientID = extras.getInt(PATIENTID);             String _itemex = extras.getString(ITEM);         }     } }</pre>	
Allergies Class	AllergiesAddEdit Class	AllergiesView Class

Figure 9.3: Class Implementation

During development of the prototype, all the classes related to decision making were kept in a single package. The overall structure of the development environment is shown in Figure 9.4 along with the packages.

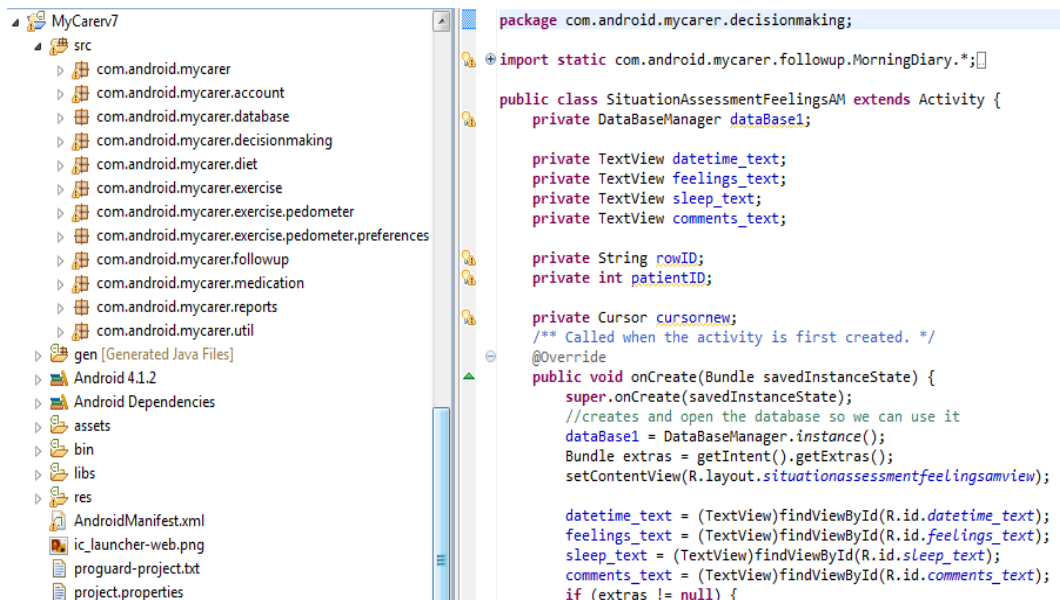


Figure 9.4: Implementation

The prototype for self-care decision support was named as ‘Smiles’.

## 9.6 Phase Summary

As at-home healthcare systems become more important for preventive healthcare, it is essential to involve end-users from project initiation through to testing such systems and thereby uncovering concerns before it is too late to address them. This chapter sheds light on improving the design and in increasing user perceptions towards the technology through an iterative process. This chapter suggests that, even though healthcare technology adoptions are affected by numerous factors including benefits, ease of use, intention to use, privacy,



and trust, involving end users from the inception of the project will not only help us to overcome these barriers but also help us to deliver easy to use, trustable systems that meet patient needs.

## Chapter 10 PHASE VI EVALUATION

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*“The aim of a decision aid is to improve decision quality and to reduce related unwarranted practice variations by (1) providing facts about the condition, options, outcomes, and probabilities; (2) clarifying patients’ evaluations of the outcomes that matter most to them; and (3) guiding patients in the steps of deliberation and communication so that a choice can be made that matches their informed values.” O’Connor et al (2007; pg 717)*

This phase is used to verify, validate and evaluate the CISDA process and the decision support. This chapter starts with guidelines for the developers to help in the implementation process followed by a case study for this phase. The challenge of evaluating prototypes lies in deciding what to draw a comparison with. Any evaluation requires a reference model (Baber, 2015) but in this thesis there is little to use as a reference. Therefore, this thesis uses user-centered design and use case evaluation techniques to verify, validate and evaluate the decision support and CISDA process. However, each one of the approach provides evidence towards the question of whether the prototype could be beneficial for supporting decisions and CISDA process effectiveness. None of them will definitively answer this. Indeed, the only means of knowing whether the prototype can support decision making by patients is to provide them with a fully-functioning prototype. However, as discussed later in this thesis, such a study was beyond the scope of the work.

### 10.1 Evaluation Phase Guidelines

---

#### **Purpose**

The aim of this phase is to gather feedback on the design process and the decision support provided from doctors and patients.

## **Thesis Composition**

This consists of:

- Prototype validation with CWA
- Prototype validation using the 20 case scenarios (Chapter 7).
- Verify prototype with doctors.
- Evaluate prototype with patients.
- Verifying patient's decision and doctor's perception.
- CISDA process feedback - IT and Psychologists.

## **Methods**

This phase uses:

- Questionnaire Study – Percentage analysis and quantitative analysis
- Interview using informal analysis

In addition to the above methods observation (Sekaran 2003) and long-term trials as specified in MRC could be used.

## **Participants**

Patients diagnosed with CVD from local heart support groups.

Doctors involved in UK healthcare.

IT Specialists and engineers at the IEOM Industry Solutions Conference, Dubai March 2015.

Psychologists and IT researchers at the University of Cambridge, UK.

## **Outcomes**

Verify the CISDA framework process and decision support prototype developed.

### **Quality Criteria**

1. Are the prototypes consistent with the modelling and interface analysis?
2. Do the prototypes provide adequate support to meet self-care and decision making needs?
3. Is the design process consistent?
4. Has the user interface evaluated with the end users and subject matter experts?

## **10.2 Prototype Validation with CWA**

---

The focus is on validating the prototype decision making support against CWA (Chapter 7) using an example decision problem to identify how the decision making process is supported.

### **10.2.1 Purpose**

This evaluation is used to check as a first step that the final design has not lost the original CWA analysis after translation to UML and implementation.

### **10.2.2 Method**

The doctors (chapter 6) during the discussion of case scenarios suggested that they encounter decision problems which are uncertain like “Tiredness/ Feeling Unwell”. This finding was also found in case scenarios (CS 1 and CS2, Chapter 6). Moreover, a chronic disease self-management book (Lorig et al., 2012) suggest that ‘Tiredness/ Feeling Unwell’ is one of the common complaints of CVD patients and can be due to many causes including medication, physical activity, diet, sleep, and other factors. “Tiredness/ Feeling Unwell” is taken as an

example to analyse the CWA Decision Ladder, Strategies Analysis and the prototype support.

### 10.2.3 Analysis

To evaluate CWA against the prototype, first the scenarios for ‘Tiredness/ feeling unwell’ need to be represented in the decision ladder, strategies analysis and prototype screens as shown below:

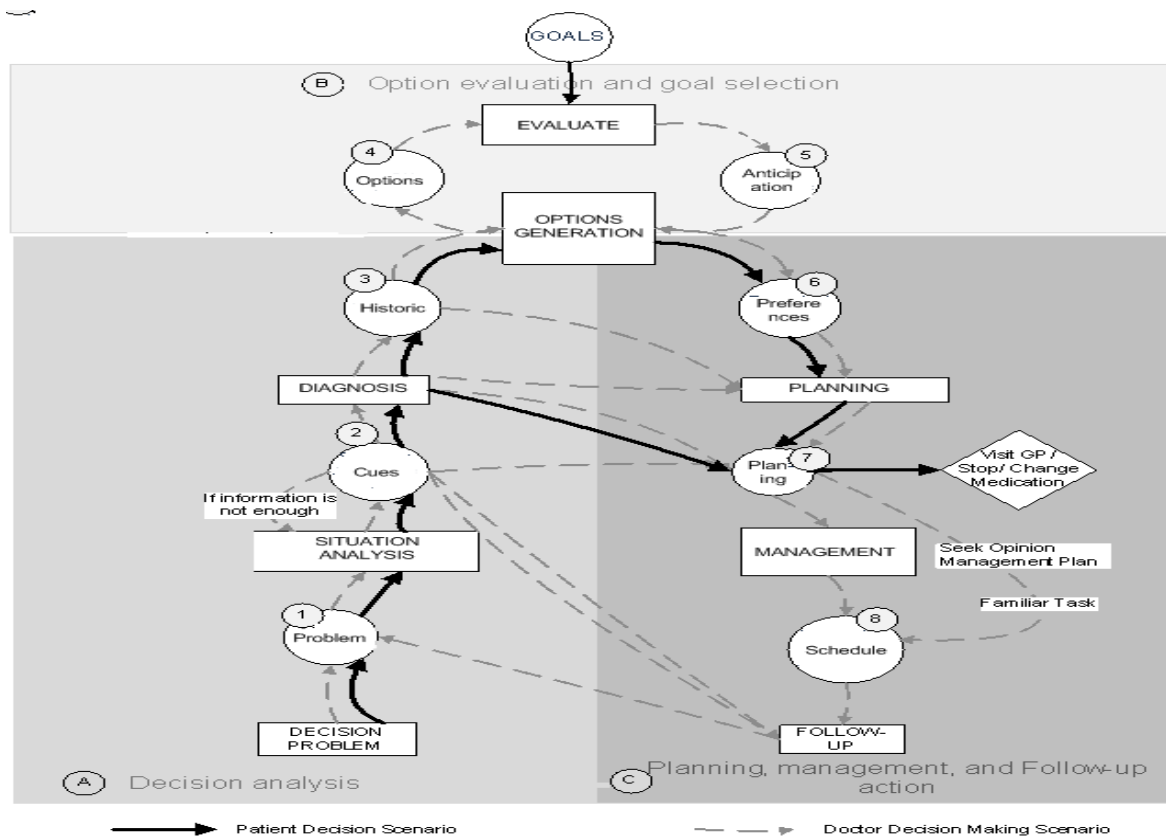


Figure 10.1: Decision Ladder for Tiredness/ Feeling Unwell (represented by numbers) are mapped on to user interface and strategies analysis shown below

### CWA Decision Ladder – Tiredness/ Feeling Unwell

- Develop decision ladder based on Chapter 7 approach to represent the patient scenarios (CS1 and CS2 Chapter 6) for ‘Tiredness/ Feeling unwell’.
- Map the doctor’s approach to supporting patients in their decision making.

- c) Each of the decision points is numbered to show the state of knowledge that needs to be achieved. Based on the numbering the screen shots from the prototype are shown to support the data processing as seen in Figure 10.1.

### Strategies Analysis – Tiredness/ Feeling Unwell

- a) Based on the decision ladder, strategies analyses are created to represent ‘Tiredness/ Feeling Unwell’ scenario. Five different courses of action are identified as shown in Figure 10.2.
- b) The strategies analyses are numbered based on the numbering associated with the decision ladder to represent the stage and the courses of action that could take place.

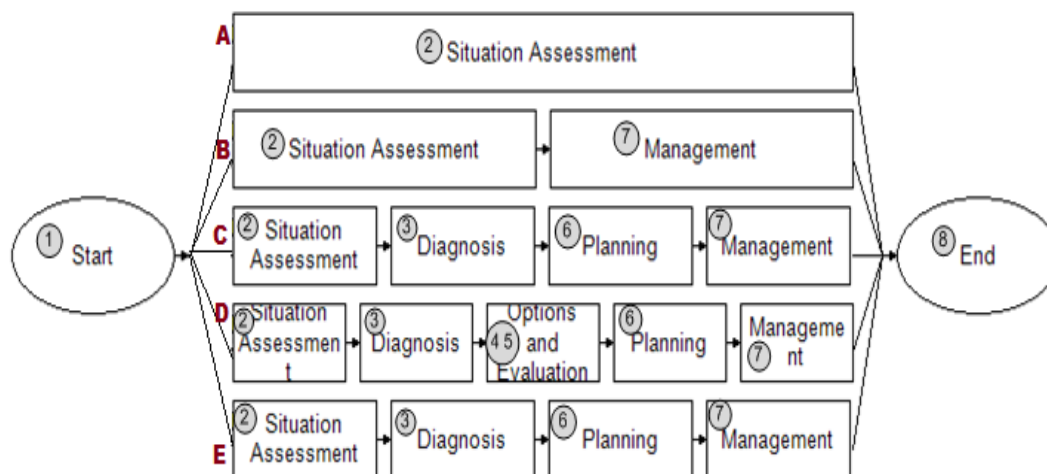


Figure 10.2: Strategies Analysis (represented by numbers) are mapped on to user interface and decision ladder. The alphabets (A, B, C, D, and E) represent the courses of action

#### 10.2.4 Results

The prototypes are compared with strategies analysis as shown in Figure 10.3 to find the support for various courses of actions (Figure 10.2). The numbers in screen shots correspond to the decision ladder stages (Table 10.1) and strategies analysis representing the course of action shown (Table 10.2). Each letter indicates a specific path of action from start to end and each path includes a different combination of actions.

Table 10.1 Prototype representation using CWA AH and Decision Ladder

Decision Ladder(Stages)	Prototype (Number corresponds to Figure 10.1)	Comments
1. Problem		Patient enters the problem and the problem gets recorded. Send message is currently not supported in this prototype.
2. Cues		Patient distinguishes the problem based on his pattern in sleep and feelings for the last three days and get more information by clicking on the images as shown in the images here.
3. Historic		Shows the status on patients diet and medicine intake and exercise for the last three days. Clicking on the images would provide more information. 'More info'.
4, 5. Options		Provides various authorised sources of information or options to call GP to discuss the problem or to arrange appointment.
6. Planning		Patients can set their action plans for preventing or controlling problems.
7. Management		Provides generic advice for decision a decision problem

Table 10.2 Prototype representation using Strategies Analysis

Course of Action	Strategies Analysis Steps	Prototype Support
A	1. Start; 2. Situation Assessment; 8. End	
	1. Start; 2. Situation Assessment; 7. Management; 8. End	
C	1. Start; 2. Situation Assessment; 3. Diagnosis; 6. Planning; 7. Management; 8. End	
	1. Start; 2. Situation Assessment; 3. Diagnosis; 4&5. Options and Evaluation 6. Planning; 7. Management; 8. End	



The results of this study shows that prototype supports CWA using various courses of action showing the flexibility provided by the system to support different learning process and experience of the patients. For e.g., experienced user may go through 3 screens to arrive at a decision (A, Table 10.2). Novice user may go through the information seeking behaviour, hence will have to navigate through 7 screens (B, Table 10.2) in their decision making process. The prototype also allows patient to go back and forth to review their activity.

The study results show the support for reducing complex behaviour of decision making into simpler process (reduction), guiding the users through the decision process (tunnelling) and providing information based on the user's activity (tailoring).

#### **10.2.5 Summary**

Although it is expected that the screens map on to the CWA as they were designed based on the analysis. Chapter 2 shows a lack of evidence in using theory or modelling tools in decision aid analysis and design. CWA was used in the CISDA to provide insight into behaviour as well as future opportunities for supporting positive interactions between human, environment, organisation and technology. It is worth addressing how the CWA approach has contributed to prototype design and support in decision making. There is also some criticism that decision aids are designed based on assumptions, so this section helps to validate the support and decision process. The point of doing this analysis was a 'sanity check' because it is quite possible for the software development (and the constraints it imposes on design) to lead the design away from the theoretical framework and CWA which is used to represent the user activity. Evaluating the prototype against CWA shows that:

- CWA provides the flexibility and support needed to support different learning capabilities and patient experiences.

- The prototype supports various courses of action for decision making that has been identified for the ‘Tiredness and Feeling Unwell’ scenario.

Moreover, this study shows that CISDA approach supports Lorig et al., (2012) study on self-management tasks based on over 20 years of research that for ‘Feeling Unwell’ self-management involves: identify the cause, isolate possible causes and effects, and action plan to overcome tiredness.

### **10.3 Prototype Validation with Case Scenarios**

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In this section prototype is validated against the twenty patient decision scenarios collected in Chapter 6.

#### **10.3.1 Purpose**

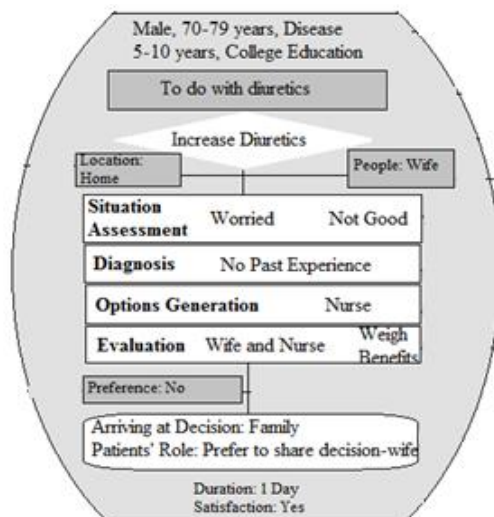
The purpose of this validation is to see how the final prototype supports patient decision making.

#### **10.3.2 Method**

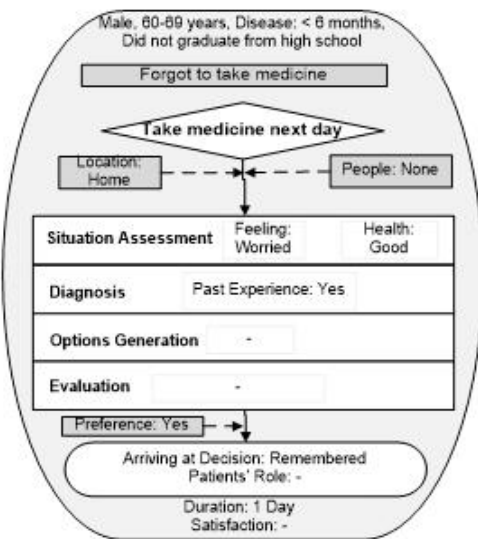
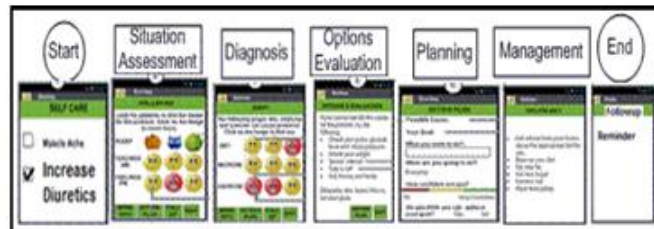
The 20 decision case scenarios collected from patients in Chapter 6 is used to evaluate the decision support prototype.

#### **10.3.3 Analysis**

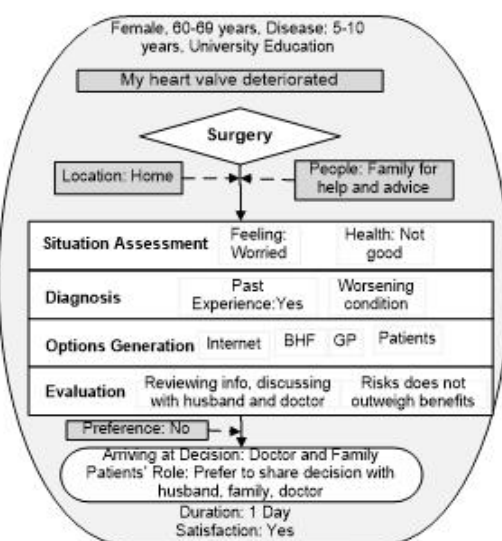
Figure 10.3 shows three case scenarios from Chapter 6 along with the prototype steps to support the decision process. For example, in CS1 (Increase Diuretics), the patient checks the feelings over the past three days, can view past experiences in the diagnosis page and gets information for options and evaluation and makes a decision.



CS1



CS3



CS4

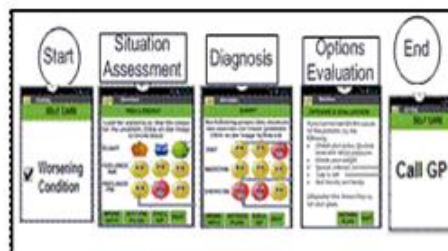


Figure 10.3 Evaluation using Case Scenarios (CS1, CS3 and CS4 Chapter 6) with Prototype

In CS3, (Take medicine next day), the patient assesses the situation, uses previous experience and sets reminders to take medicine. In CS4, the patient needs to decide on surgery, although the focus in this thesis is on supporting everyday self-care decision making that is 'to do' or 'not to do' with something, the prototype shows how patient can make surgery decisions. Mapping these scenarios to the prototype shows the flexibility achieved in the design for supporting different decision making situations.

This study shows that the prototype provides support for all of the 20 decision scenarios collected in Chapter 6. This shows that the descriptive framework using NDM decision theory has helped in translating decision making using the features into the design. Like in the previous study, it is expected that the screens map on to the case scenarios as they were used as the basis for carrying out modelling and development. However, as there is a lack of evidence (Chapter 2) in using theory or modelling tools in decision aid analysis and design, this study shows that due to consistency and a systematic approach it is possible to not only integrate needs assessment, theory and modelling into the design and develop but also to re-engineer the process.

## **10.4 Verify Prototype with Doctors**

---

This study verifies prototype with doctors to assess the decision support provided.

### **10.4.1 Purpose**

This study verifies the prototype with doctors to check if it will effectively and reliably serve patient's self-care and decision making needs before giving to patients.

### **10.4.2 Participants**

The doctors who participated in the Chapter 6 study were approached for the prototype verification as they were familiar with the study. All the doctors in Chapter 6 were contacted and three doctors (2 females and 1 male) immediately agreed to participate. It was decided if there were lots of discrepancies in the prototype then further evaluation would be carried out.

### **10.4.3 Method**

The study was carried out in a 45 minute session involving:

- First, presenting the mobile phone app so doctors could browse the functionalities and see how patients would navigate. This was also designed to provide an ‘out-of-the-box’ experience, without any introduction or explanation of use.
- Next, the paper prototype was verified with doctors.
- Doctors were given 10-15 minutes to go through the paper prototypes.
- Finally, doctor’s feedback on each screen were noted.

### **10.4.4 Results**

Doctors mentioned a few additions/ suggestion to the application:

- Doctors use the word ‘mood’ rather than ‘feelings’ so they felt it would be appropriate to use ‘mood’.
- Display the last 7 days of self-management activities (if possible).
- For advice it is better to link patients to <http://www.patient.co.uk> website as that would provide useful information to patients.

- As alcohol and smoking are important in self-management it should be available for patients in the front page along with diet and exercise. Currently this is supported in diet.

Apart from the above improvements there were no disagreements in the approach, content or representation of data.

Table 10.3 shows doctors' feedback on the screens along with the codes based on the screen numbers as shown in Table 10.1 and 10.2.

*Table 10.3: Doctors Feedback on Prototype*

Code	Doctors feedback
1	"These (muscle ache and feeling unwell or tired) are very common problems we face". (Doctor 3)
2	"It will be good if patients can see the pattern over last 7 days" (Doctor 1) also suggested by other doctors  "We use 'mood' rather than 'feelings'. (Doctor 3)
3	"Again need to show for the last 7 days" (Doctor 1), also repeated by other doctors.
4 & 5	"You cannot do much here other than referring to the websites" (Doctor 2).  Doctors' took some time to see how this can be improved and mentioned that nothing much can be done here to improve rather than providing information.
6	"This I think is important, because patients forget what was decided" (Doctor 1). Doctors felt that the action plan along with the reminder should enhance patients adherence to decision making.
7	"Where did you get this (advice) information?" (Doctor 1, 2 and 3)  "We always refer to <a href="http://www.patient.co.uk">http://www.patient.co.uk</a> . It is specially designed for patients." (Doctor 3) All the doctors mentioned that for management, it is better to link to the website <a href="http://www.patient.co.uk">http://www.patient.co.uk</a> or reproduce the contents from the website which doctors refer to patients. The website has been specifically designed to provide information to patients for various conditions.
8	Doctors thought summarising the decision making process was a good idea to reinforce patients' decision and the action plan.

### **10.4.5 Summary**

The main focus of this study was to get expert opinion to verify the prototype for decision support. Although doctors gave a few suggestions for improvements as mentioned in Table 10.3 since there were no concerns on the CISDA approach or guidance for self-management, the current prototype were evaluated with patients. Overall, doctors felt that this kind of mobile application would be useful to self-manage any chronic disease to improve patients' self-awareness and to take control of their well-being. As there were no concerns on the approach or guidance, the prototypes were further evaluated with patients to understand their perception.

## **10.5 Evaluate Prototype with Patients**

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This part of the study was used to evaluate paper prototype with patients already diagnosed with CVD using presentation of the prototype and video.

### **10.5.1 Purpose**

The purpose of this study was to evaluate the prototype with patients: (i) to identify if the prototype supports patient's decision making, (ii) their decision process, (iii) gather patient's feedback and (iv) perceived usefulness.

### **10.5.2 Participants**

Thirteen heart groups in the Midlands were contacted for the study by email. Five heart groups showed interest, but due to various pre-booked heart meetings it was not feasible to conduct study with all the groups. Dudley HUGS heart group, Cheshire Heart group and Heartlands support group in the West Midlands were selected based on their availability. Participants were recruited as mentioned in Chapter 4. Twenty-Four participants (eleven

females and thirteen males) volunteered for the study. 22 patients were new to the study and 2 of them have been involved throughout the study. Participants aged from 40 to 99 years old with CVD of six months to 10 years from diagnosis.



Figure 10.4: Video Demonstration



### **10.5.3 Paper Prototype Design**

The paper prototype was used due to the limited number of mobile app for the patients in the study. The paper prototype was designed similar to browsing the mobile app. Each screen shots were in separate pages in a booklet format with page numbers for the action buttons in the mobile screen.

### **10.5.3 Method**

This study was conducted in three places with 5 patients at the Heartlands Hospital, 7 patients at Cheshire and 12 patients (into two groups of 5 and 7) at the Dudley Hugs meeting centre. Similar to the study involving doctors (described above), a mobile phone application along with paper prototype was shown to the participants. This study was conducted using focus group method for about 30-40 minutes in a sequential process as follows:

- Introduction was given to this study including the need and why it was designed.
- Mobile phone app was shown to the participants for quick browsing.
- The evaluation was carried out using pre and post-test (Chapter 4, 4.8.3) to fill in a questionnaire with their demographic details (Appendix F). In the pre-test questionnaire a hypothetical decision problem (Table 10.4) was presented to the participants and the participants were asked to give their advice as to what the patient in the hypothetical scenario should do. This part is used to compare patients' responses to decision problem before and after going through the prototype.
- Next paper prototypes were shown to the participants followed by a video demonstration to help participants understand the application of the prototype as shown in Figure 10.4.

- Participants were asked to go through the paper prototype and mark the steps involved to guide the patient in the hypothetical scenario for arriving at a decision.
- Finally, a questionnaire was given to the participants to collect their feedback about the paper prototype (Appendix J). The questionnaire uses 3-point Likert scale as the patients had to answer perceived usefulness questions in addition to the demographics questions. So 3-point scale was used to reduce the amount choice and so ease of use.

*Table 10.4: Hypothetical Decision Scenario*

<p>SCENARIO ONE: One year ago, Ann, 64 years old, was diagnosed with congestive heart condition. Ann has been managing well. From today morning she is feeling tired. She is not sure of the cause or what to do. What would you suggest to Ann? (please choose 2-3 options and number them based on priority):</p>		
<input type="checkbox"/> See the GP	<input type="checkbox"/> Be active	<input type="checkbox"/> Due to poor diet
<input type="checkbox"/> Weight problem	<input type="checkbox"/> Related to emotions	<input type="checkbox"/> Due to medications
<input type="checkbox"/> Not enough sleep	<input type="checkbox"/> Other.....	

#### 10.5.4 Analysis

The results from pre and post-test are shown below.

##### *Pre-test*

23/24 participant's response to the hypothetical scenario question (Table 10.5) was to see GP for advice. Only one participant responded as 'related to emotions'.

##### *Post-test (After Prototype Presentation)*

After presenting the video demonstration 19/24 participant's response to the hypothetical scenario changed (Table 10.5). Patient's response to scenario was as follows:

- 6/24 "See GP"
- 10/24 "Due to medications"

- 4/24 “Not enough sleep”
- 1/24 “Related to emotions”
- 2/24 “Look at SMILES (the prototype) record”
- 1/24 “Be active”

Although the results were encouraging to see a change in patient’s decision making except for 5 patients, some limitations need to be acknowledge. These studies can have halo effects in presentation of the video/ prototype which can influence response between pre and post-test, hence the patients were encouraged to provide feedback or justifications on their change of decisions and also their perceived usefulness of the prototype.

The 5 patient’s decisions did not change; this may be because two patients do not have a mobile phone as shown by patient’s comments below:

"I found it very difficult to answer as I don't have a mobile phone (aged 70-79, 10 years of CVD)."

“We have no mobile phone available at the moment (aged 70-79, 5-10 years of CVD)."

This raises a question: Why a mobile app when some of the patients do not have mobile phones? Even though few patients were not used to smart phones, mobile application is increasingly used in healthcare system as it enables various features such as internet access, data storage, alarm functions, global positioning system (GPS) guidance and email (Demidowich et al., 2012). In future it is expected that smart phone usage will be getting more common. As mentioned in section 5.5.1.5, this thesis uses smartphone app prototyping so that patient can access the recorded data about their health and well-being anytime, anywhere. Other two patients found the app complicated and were very sceptical of using the app as shown below:

"Would not use as it is complicated for me (aged 70-79, 5-10 years of CVD)".

"This system for me is far too complicated (aged 60-69, less than 6 months of CVD)".

This may be because patients were not used to mobile apps or the design of the interface. As the design of the prototype involved only few iterations further iteration would have been helpful. As mentioned in section 9.3 prototype can be improved through the application of persuasive design models suggested by (Torning and Oinas-Kukkonen 2009). Apart from the four patient concerns rest of the comments seem to be mostly positive as shown below:

"I am not sure how to use the app, but I think it is a good idea (aged 70-79, 5-10 years of CVD)."

"Should give confidence in self-management (aged 70-79, 5-10 years of CVD). "

"I would recommend to others: "If I was happy about using it myself" (aged 70-79, 5-10 years of CVD)."

"I like the title SMILE. Chronic illness you need to manage longer. I like the choice you have to put in about diet, emotions (aged 90-99, 10+ years of CVD, retired GP)."

"This should help me in my daily life (aged 50-59, 5-10 years of CVD)."

"Could be a useful individual diagnostic tool (aged 60-69, less than 6 months of CVD)."

"This should be very helpful (aged 40-49, less than 6 months of CVD)."

"The app could lead to patient's make errors in self-diagnosis

"I feel this should help a person of a suggestive nature perhaps find symptoms that clinically may not exist (aged 70-79, 5-10 years of CVD)".

"Good basic idea but might be giving too much info leading to hypochondria, white coat symptoms (aged 80-89, 10+ years of CVD)."

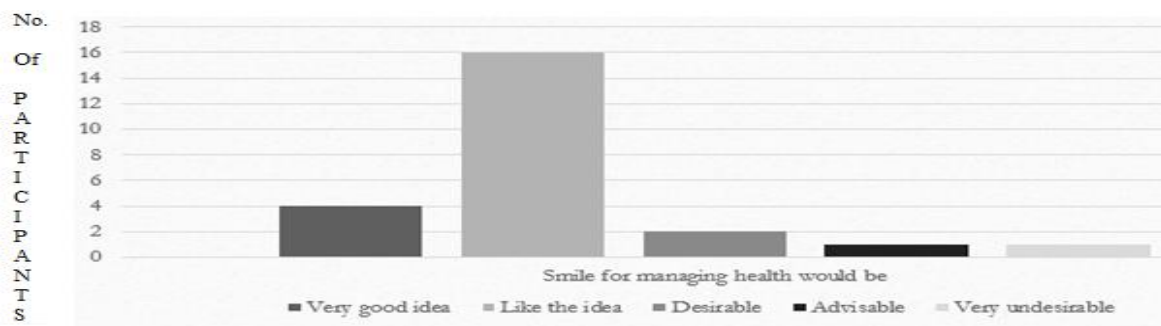
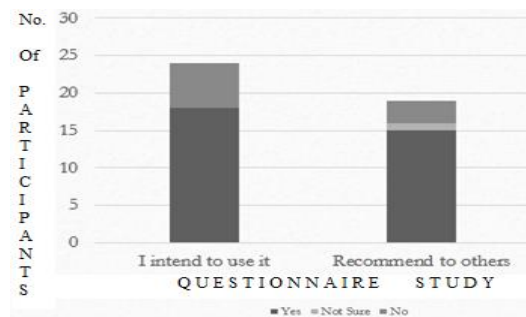
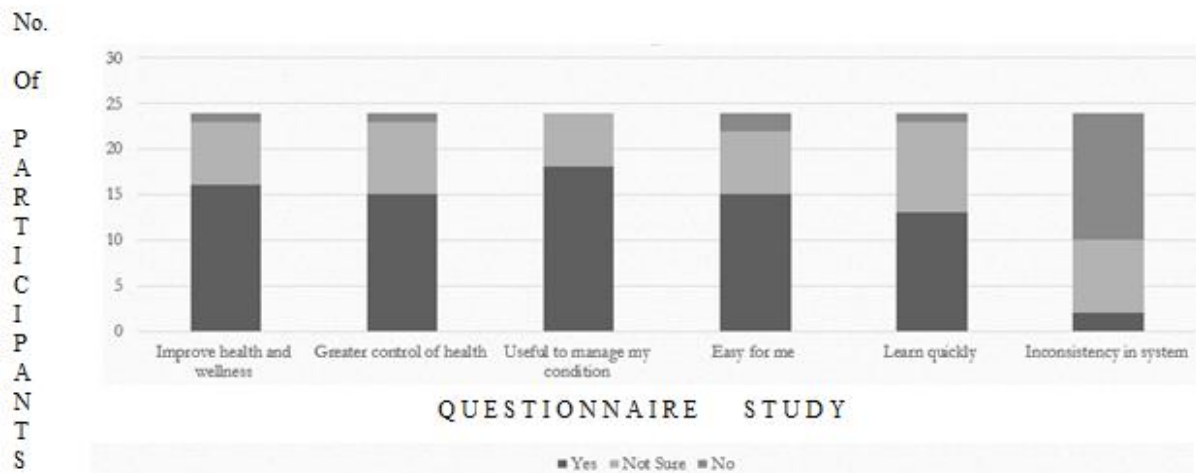
"It is interesting (aged 70-79, 5-10 years of CVD, retired GP)."

Although there might have been some bias in pre and post-test, the positive comments from study group suggests that prototype could help the patient being empowered in self-managing their chronic condition, making day to day decisions related to their health. However, few patients raised the possibility of being over cautious with the trivial symptoms. Overall, the prototype is aimed at improving self-awareness of patient's day to day wellbeing and decisions.

### ***User Perception***

Tables in 10.5 show patient's response regarding perceived usefulness and ease of use. Patients have been very positive about the prototype. This shows that the CISDA process has helped to develop system to address user needs.

Table 10.5: Perceived usefulness

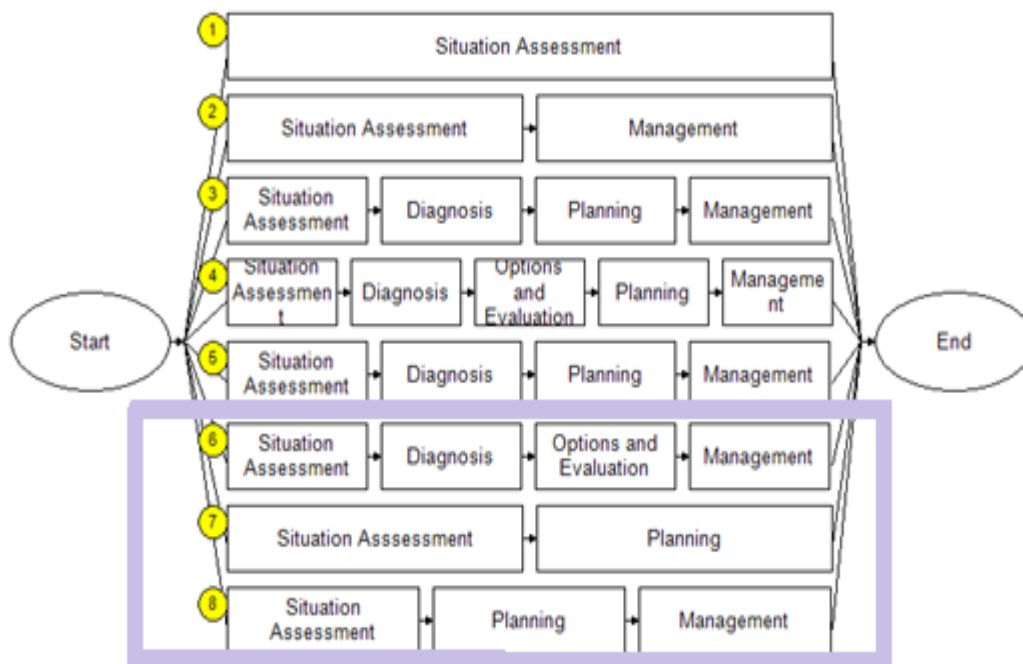


### 10.5.5 Discussion

#### *Support for Decision Process*

Further to pre and post-test, the patient's decision process in solving the hypothetical scenario were observed to understand the decision process and their thought process for further evaluation. Observing participants approach to decision making using paper prototype shows

that most of the patients' decision making can be supported using one of the eight courses of actions as shown in Figure 10.5.



*Figure 10.5: New Course of Actions based on patient's evaluation*

On discussion with patients during the analysis it was found that the current prototype system allowed flexibility in guiding the patients it does support new courses of action as shown in Figure 10.5 numbered 6, 7 and 8. For e.g., there was no link for participants to go from Options and Evaluation to Management without action planning. This shows that the design is an ongoing process. Participants found that management advice needs to be dictating what patients should do for the decision problem. This shows that doctors just do not expect patients to be compliant by following their advice (Chapter 2) but some patients also wanted to be treated like that. To satisfy these needs, the current prototype gives some general advice for patients with the <http://www.patient.co.uk>. Although some patients suggest that this could lead to hypochondriac effect.

The prototype does not provide a detailed diagnosis for pain management. For example, if the patient has pain in the chest, doctor diagnosis involves identifying the location of the pain and the severity of type along with vital signs and symptoms. This level of diagnosis would require a medical decision aid developed based on medical expertise. This is why it makes so much sense NOT to include matter which could be diagnostic. It would make far more sense for ‘muscular pain’ to advise the patient to seek medical help, making a note of what they had been doing by looking at their activities, exercise, diet and medication. Due to some bias in pre and post-test, further testing was carried out using questionnaire for understanding the perceived usefulness of the app.

#### **10.5.6 Summary**

Although there might be some bias in the pre and post-test, the evaluation shows some change in decision making in the post-test which was also reflected in the patient comments. Moreover, the change in decision is supported in the results section showing positive results gathered from the perceived usefulness questionnaire study. On observing patients in their decision making process, it was found that the prototype supports knowledge gathering process by reflecting and assessing their condition based on sleep, feelings, diet, exercise and medication pattern. Patients seem to use different courses of action which have been identified through CWA along with some new courses of action. Patient’s response to ‘learn to use’ ranked less than the other perceived usefulness. This may relate back to the introduction of a new process to patients using mobile phones, which was relatively new to them as they have been using phones for just making calls as discussed in section 10.5.4.



## 10.6 Verifying Patient's Decision Making and Doctor's Perception

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This part of the study is used to verify patient's decision making and the usefulness of the prototype developed with the doctors.

### 10.6.1 Purpose

The purpose of this study is two-fold: (i) verify patient's decision making from section 10.5 with doctors using the hypothetical scenario (Table 10.4) and (ii) doctor's perception of the usefulness of the support developed using the CISDA.

### 10.6.2 Participants

Doctors not involved in this research were recruited for this study to get a new perspective. Initial contact was made through the GP surgeries and visiting GP at their teaching or meeting sessions. Interested GPs were emailed about the study details and were asked to forward to their colleagues and friends. Six GPs showed interest but only 5 participated. All the five doctors (3 males and 2 females) were engaged in full time general practice from different parts of England with the experience ranging from 16 to 22 years post qualification.

### 10.6.3 Questionnaire Design

The questionnaire for accessing doctor's perception was developed based on Ottawa Health Research Institute's (OHRI) 'CREDIBLE' checklist for quality assessment of decision aids (Elwyn et al., 2006), IPDAS Categories of quality items, and O'Reilly's (2014) study on evaluating chronic disease management. The questionnaire is organised into three sections: (i) usefulness to patients, (ii) in practice planning and (iii) decision support. The questions in this study were phrased using a 5-point Likert scale, where *completely agree* was used to refer to a positive response and *completely disagree* to a negative response. 5-point Likert

scale was used as it was found to produce slightly higher mean scores, although not used in this study (Dawes 2008).

#### **10.6.4 Method**

The verification method is similar to the above patient pre and post-test including:

- 1) Presentation of hypothetical Ann's scenario (Table 10.4) to the doctors and the response was noted in pre-test.
- 2) Next the video of how Ann could manage using the prototype is shown and same Ann's scenario in pre-test was presented and response was noted.
- 3) The doctors were presented with the results of the same survey done among the patients and asked to verify patient's decision.
- 4) Further, questionnaire was given to gather doctor's perception on the usefulness of support developed using the CISDA process.

#### **Pre-Test**

The hypothetical scenario (Table 10.4 as presented to patients) was presented to General Practitioner (GP). During the pre-test all the five doctors chose that Ann should see the GP to get checked and did not suggest any other option.

Later, GP's were presented with a short video on how Ann could make a daily record of her sleep, emotions, diet, medications and activities in the smartphone and review that information for the previous 3 days to analyse the reason for her tiredness and the course of action.

#### **Post-Test**

Following the video GP's were presented with the same Ann's case scenario. This time doctor's chose "Medications", "lack of sleep" or "emotions" as the reason for Ann's tiredness.

This analysis shows that doctors also changed their decision making as did patients.

### 10.6.5 Results

#### Verification of Patient's Decision

Doctors were asked to verify/ rate patient's decision as 'good' or 'bad'. In general, doctors mentioned that decision making is individualistic considering the problem, circumstance, patient's experience and knowledge. Doctors rating of the decisions made by patients is shown in Table 10.6.

*Table 10.6: Verification of Patients Decision Making with Doctors*

Be active	All the GP's were in complete(4) or strong agreement(1) with the patient decision
Not enough sleep	All the GP's were in complete(3) or strong agreement(2) with the patient decision
Due to Medications	All the GP's were in complete(4) or strong agreement(1) with the patient decision
See GP	None of them completely agreed with this decision but equivocal (2) or strongly agreed(3)

#### Doctor's Perception

Next doctors were presented with a questionnaire to analyse their perceived usefulness of prototype.

Table 10.7: Doctor's Perception on the Prototype

Question	N	Completely Disagree	Somewhat Disagree	Slightly Agree	Mostly Agree	Completely Agree
<b>Usefulness to Patient</b>						
It would help patient's in their decision making process	5	0	0	1	2	2
It would provide a useful support for patient	5	0	0	0	0	5
It would help patients to better self-manage	5	0	0	0	3	2
TOTAL		0%	0%	7%	33%	60%
<b>In Practice Planning</b>						
It would assist in consultation	5	0	0	3	0	2
It would help me to quickly review the patient's status	5	0	0	0	2	3
It would help me to quickly review the patient's trends	5	0	0	0	1	4
It would assist in my consultation with patients	5	0	0	1	1	3
It would assist me to provide patient education	5	0	0	0	1	4
It would improve the quality of consultation time with the patient	5	0	0	0	1	4
TOTAL		0%	0%	13%	20%	67%
<b>Decision Support</b>						
Decision making process is simple to follow	5	0	0	0	0	5
Options and values are easy to evaluate	5	0	0	0	0	5
Reduce decisional conflict	5	0	0	0	3	2
Would improve patient decision making	5	0	0	1	1	3
Are compatible with how I think patients should make decisions with regards to the decision problem like "tiredness" and general problems	5	0	0	1	2	2
I would recommend it to patients	5	0	0	1	1	3
Overall, I am satisfied with the decision support	5	0	0	0	2	3
Would improve the match between the chosen option and the features that matter most to the informed patient.	5	0	0	0	2	3
Would make patients anxious	5	2	0	3	0	0
Would help patients to be more involved in healthcare	5	0	0	0	1	4
TOTAL		4%	0%	12%	24%	60%

Overall, the doctors strongly or completely agreed with patient decisions which further strengthens the argument that prototype would assist to improve patient's self-awareness and thought process in self-managing their condition. General comments received from doctors on the prototype were very positive:

"Very good application but not sure if patients would be able to record and use it regularly." (Doctor2)

“Yes will help in patient’s education and self-care.” (Doctor 5)

#### **10.6.6 Discussion**

The change of doctor’s view post video presentation strengthens the fact that the designed prototype would be thought provoking and guiding the patient in their decision process. Not only could this avoid a knee jerk reaction of contacting the doctor for trivial symptoms and overburdening the health service but also empowers the patient to make reasonable judgement about their own health and being in control. All the doctors felt the prototype would help the patients in the day to day decision making process, provide useful support and better self-manage. All of them were in agreement that the prototype would be useful to quickly review the patient status, watch their daily trends, and provide better patient education based on their need which would improve the quality of consultation time. However, three doctors were not sure how much it would help with the overall consultation process. Pertaining to the questions on design prototype two-thirds (67%) of the collective opinion were in complete agreement that prototype is easy to follow, record and evaluate. There was a disagreement for the view that the prototype would make patients anxious or too self-conscious. In general, few of the doctors were unsure how patients would be able record the information regularly and review to make it useful.

As doctor’s mentioned it is not possible to justify which is ‘good’ or ‘bad’ decision. This is because decision making is difficult to quantify as for many decisions there is no obvious ‘right’ or ‘wrong’ options (Gaston and Mitchell 2005; Kryworuchko et al., 2008). The quality of decision making depends on the concordance between what matters most to the patient and the option chosen at the time involving: (i) the elicitation of patient’s goals, treatment preferences; (ii) identification of the patient’s chosen options; and (iii) the extent to which the chosen option best meets the patient’s goals and preferences (Sepucha et al., 2013).

## **10.7 The CISDA - IT and Psychologists Feedback**

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This section tries to gather feedback from IT professionals, researchers and psychologists. This study is modelled based on Vincent and Blandford' study (2011) on the usability of a specific medical device design involving professionals to better understand the barriers and best practices.

### **10.7.1 Purpose**

The purpose of this study is to gather feedback from the industry experts including IT professionals, researchers and psychologists on the CISDA process.

### **10.7.2 Participants**

Participants for this study used the approach described in Chapter 4 (section 4.8). The survey was conducted among a group of psychologists (5), software engineers (4), research educationalists (2) and the other three with combination of all the above expertise in total of 14 participants. The professionals represented from across the globe - Middle East, U.K, America, Asia and Africa. Greater proportion of them were based at the University of Cambridge. The professionals experience varied from 2 to 20 years with a mean of 9 years where they claimed expertise on decision making, healthcare support systems, design of systems and education.

### **10.7.3 Method**

This study was carried out using a presentation and questionnaire. First the thesis presentation was given to the participants for 30 minutes including introduction to existing

approaches in the literature (Chapter 2), the gaps (Chapter 2 section 2.7), CISDA framework (Chapter 3, section 3.3), the process for developing the prototype using the 6 phases (Chapters 5-10) and the video of Ann (Figure 10.4). As the focus of this study was to access usefulness of the CISDA process, the study presentation paid more emphasis to addressing the complexities (section 11.2), filling the gaps in the literature (section 11.3), requirements extraction, theoretical framework, CWA analysis, translation of CWA to UML and evaluation of CWA. The presentation was followed by a 15 minute questions and answers section and then the questionnaire study.

#### ***10.7.3.1 Questionnaire Design***

The questionnaire for the study was developed to gather feedback from the participants on the CISDA development process used to develop the prototype. Each of the questions were used to verify the process that IPDAS stresses the need for a systematic development process and UCD 13407 stress on the need to explicitly understand users, task and environments.

#### **10.7.4 Analysis**

During the question and answer sections participants were very much interested in understanding the application of CWA especially the decision ladder and abstraction hierarchy (Chapter 7, section 7.3). The analysis of the questionnaire study are as follows.

#### **10.7.5 Results**

As the presentation paid more emphasis on the usefulness of the CISDA process in addressing the complexities (section 11.2), filling the gaps in the literature (section 11.3) through software requirements extraction, CWA analysis and translation of CWA to UML. The questionnaire study helped to gather feedback from the participants on the CISDA process.

Table 10.8: The CISDA Process Feedback Study

Question	N	Completely Disagree	Somewhat Disagree	Slightly Agree	Mostly Agree	Completely Agree
Design approach seems to be well defined with various stages	14	0	0	3 21.4%	8 57.1%	3 21.4%
Design framework provides patient-centric approach	14	0	0	2 14.2%	7 50%	5 35.7%
Needs assessment help in capturing patient needs	14	0	0	5 35.7%	5 35.7%	4 28.6%
Application of decision making theory would be useful in understanding self-management decision making	14	0	0	4 28.6%	6 42.9%	4 28.6%
Human factor analysis like CWA would help in modelling decision making	14	0	0	2 14.2%	9 64.3%	3 21.4%
Human factor analysis like CWA would help to understand decision making from various viewpoints	14	0	0	3 21.4%	9 64.3%	2 14.2%
Integration of human factor to software design would be useful to assist developers	14	0	1 7.1%	4 28.6%	5 35.7%	4 28.6%
Overall the approach seems to be useful for supporting decision making	14	0	1 7.1%	2 14.2%	8 57.1%	3 21.4%
I would use the approach for similar applications	14	0	0	4 28.6%	6 42.9%	4 28.6%
The approach would help me to consider human factors	14	0	1 7.1%	2 14.2%	8 57.1%	3 21.4%

The professionals were in agreement that a well-defined, patient centric design approach and the role of CWA to understand and model decision making. Although one participant showed slight disagreement to -"The approach would help me to consider human factors", the participants mostly agreed to all the questions.

### 10.7.6 Summary

Overall, the study showed positive feedback from the participants on various aspects of CISDA approach and its usefulness in addressing the complexities and gaps (sections 11.2 and 11.3).



## 10.8 Phase Implications and Summary

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As long-term study was not possible within the thesis timeframe and ethical constraints, this section has explored different ways to verify and evaluate the design process and decision support. One could argue that as the evaluation was carried out by the researcher involved in the design process, there might be some bias, hence the evaluation was carried out from various perspectives in pursuit to evaluate the CISDA process in providing a useful decision support. The study also shows that some of the decision process carried out by the patients was not fully supported (section 10.4).

This chapter helps in verifying, validating and evaluating the concept for developing self-care decision aids using CISDA process to guide design and development. It is interesting to note the concerns in using mobile technology (sections 10.4) due to lack of awareness and access. Although the participants felt confident that they have adequate skills to handle the technology some felt further training and access to help desk would be beneficial.

Although this chapter constitutes only a small group of CVD patients it creates a groundwork for future research. This chapter shows that:

- CISDA process is helpful in the design and development of self-care decision aids.
- Support for decision making is also found to be useful through patients and doctors study.

Although the evaluation studies have been very positive towards the CISDA process and the decision support developed, future work is to ask someone to implement the process.

## Chapter 11 DISCUSSION

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*What is the secret of success? Right decisions. How do you make right decisions? Experience. How do you gain experience? Wrong decisions- A. P. J. Abdul Kalam, Former President of India*

The CISDA design process is proposed to capture patient's needs, their decision making, modelling of their decision process, creating usable interface and evaluation. This chapter provides discussion on the proposed CISDA process along with its caveats.

### 11.1 CISDA

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Despite the advancements in technology, healthcare systems can fail when they move from systems design to deployment (Effken 2002). This may be because when systems designers are faced with the task of describing or analysing a complex system, they are often not sure “where to start” and “where to stop” or “what to do” (Sanders and McCormick 1987). Moreover, the requirements for developing individualised healthcare systems are not the same as workplace systems (Baxter and Sommerville 2011). Hence, development of successful system requires a systematic understanding and process to identify what happens in healthcare situations (Caray 2011). But French et al., (2012) shows that there is little systematic operational guidance on how to develop complex interventions that best addresses the gap between practice and evidence. To achieve this, CISDA (Chronic Illness Self-care Decision Aid) uses a systematic development process using an evidence based, user-centred framework consisting of:

- Phase I - Needs Assessment
- Phase II – Theoretical Framework
- Phase III – Modelling
- Phase IV – Integration

- Phase V – Interface Design
- Phase VI – Evaluation

The phases are linked tightly, the output of one phase becomes the input of another phase. UCD design approach is used to provide a user-centric approach involving: patients, doctors, caregivers, IT professionals and psychologists. Fisk and Rogers (1997) suggest that involving users in the design of the system enables adults to understand that they can do something to improve their memory to enhance their health and well-being. Also users will have a feeling of control over the system (Norman and Draper 1986).

### **Phase I – Needs Assessment**

This phase helps in the functional requirements extraction for self-care management. Power (2011) suggests that decision aids have not shown any impact on patient satisfaction or general quality of life or demonstrate effective assistance to patients. ISO 9241-210 recommends the need for explicit understanding of the users, their tasks and environments. Understanding users help to better address physical and cognitive demands of the patients (Stronge et al., 2007; Rogers and Fisk 2001). Due to this lack of understanding, DAs seem to focus on clearly defined rules and procedures or in information provision (Hubbard 2008; McCaffery 2007; O'Connor et al., 2004).

### **Phase II – Theoretical Framework**

This phase extracts software requirement specifications needed for supporting self-care decision making based on the proposed theoretical framework (Table 7.7) for decision making. The framework was derived from doctor's consultation model and NDM features (Klein 2008) as described in sections 6.2 and 6.4, it also considers various attributes or cues for decision making. The proposed framework is supportive rather than a replacement of

other methods providing sufficient information (such as situation assessment – diagnosis – options generation – evaluation) that is necessary to describe decision making.

In a review by Arnott et al., (2004), half of the published DAs were not grounded in judgement and decision-making research. Conventionally, DAs have emphasised information needs, however, there is growing evidence that people do not make decisions just based on the information they receive (Mathers 2012). People in general use various approaches in decision making so applying theories to decision making helps to examine how individuals make, what options they have (Elwyn 2011) and the factors that affect their decision process (Carayon 2011). Application of decision theory helps to describe and explain behaviour in an attempt to predict decision making (Durand et al., 2008). Bekker (2010) specifies that theory application is fundamental to the operationalisation and evaluation of decision aids.

### **Phase III – Modelling**

Chapter 2 shows that there is lack of evidence in modelling and extracting requirements for supporting decision making. CWA analysis provides a high level view of the system by extracting and synthesizing decision making from different perspectives: decision processes, work organization, patient competencies and strategies used in decision making. Models are essential to provide a descriptive analysis of decision making (Durand et al., 2008). The CWA analysis has helped to model patient in a goal-relevant manner especially in unanticipated situations and in explicitly structuring of patient's decision making using structural means-ends, part-whole and casual links to navigate the problem space easily (Hajdukiewicz et al 2001). Ernst et al., (2006) study shows that CWA (Chapter 7) helps to capture social interaction coupled with different perspectives on the problem and a degree of automation with uncertain quantitative data.

## **Phase IV – Integration**

This phase could be used for various purposes – integration of different systems (hospital/healthcare systems, monitoring systems, database), integration of various resources for supporting decision making or as in this chapter integration of human factors analysis (CWA) with UML for software design and implementation. The integration phase was developed based on the feedback received from researchers (section 7.4). The main challenge is in translating CWA systems analysis into software specifications.

This challenge comes from different languages used by human factors, systems engineers and software developers (Handley and Smillie, 2010). As Bruseberg (2008) notes, “Human Factor practitioners and SE [Software Engineering] practitioners often find that there are communication difficulties.” (p.220). One of these communication difficulties stems from the different focus that the two approaches might place on the system under consideration, while another might come from the different design methods that the approaches use. The need to describe the domain of the problem and the challenges faced by people who work in that domain is quite different from the need to specify a solution to the problem. This results in a very different understanding of the nature of ‘design’ and part of the challenge is to bridge the gap between what design means to the Human Factors engineer (which is primarily to gain insight into the problems that users face and suggest solutions to these problems) and what design means to the system or software engineer (which is primarily to specify a complete and coherent system which can address the problems that users face). While there may well be overlap between these different views of design, in practice they are sufficiently far apart to create problems (Skilton et al 1998; Alter 2009; Baxter and Sommerville 2011). To achieve a coherent understanding of the human systems integration,

there needs to be clear ways to combine human-centred and software engineering approaches to interface design and development. The various level of CWA and the UML translation helps to understand how an individual human interacts with a system and develop the interface based on that. Therefore, by applying UML modelling to the output of CWA, it is easy to bridge the gaps for the design and implementation.

### **Phase V – Interface Design**

The literature review (Chapter 2) almost all the studies were aimed at achieving usability but less importance is paid to this phase in the development process. Very few studies have specified how the design of interface was carried out. This phase helps to bridge the gap between people and systems and suggests that users develop a mental model of the system hence it is important to capture the mental model and convert it to the design model to provide a better support (Norman & Draper 1986). Winkelman et al. (2005) propose that simply providing technology to patients may have little benefit without also providing a sense of ‘illness ownership’ (by the patient).

### **Phase VI – Evaluation**

Evaluation as specified in the MRC (Campbell 2000) plays an important role in verifying and assessing the usability and effectiveness of the system. It is not possible to test absolutely every process or task supported in the prototype, but the evaluation tries to analyse the prototype, decision support and the CISDA process through various studies for verifying, validating and evaluating the CISDA process and the decision provided with patients, caregivers, doctors, IT specialist and psychologists.

The goal of evaluation is to advance the fundamentals of decision making and improving the CISDA process for enhancing health and well-being of chronic patients. There is a pressing need on healthcare systems to provide “high-quality” support for self-care which involves

decision making. Determining “high-quality” decision making is highly debated in the literature. Some studies claim that (Barnato et al 2007) decision making should help in the overall comprehension and provide a close match between patients’ stated values and chosen option. The evaluation study does provide encouraging results on the decision process, support and CISDA process.

## **11.2 Briefly Revisiting Complexities**

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Section 1.2 (Chapter 1) highlighted some of the complexities involved in supporting everyday self-care management decision making. This thesis is not focused on addressing one of the complexities, but consideration is given to all the complexities. This section shows how the thesis has addressed the complexities.

### **11.2.1 Decision Ambiguity and Uncertainty**

Research questions 1 and 2 (section 1.4) has helped to address this complexity. Chapter 5 gives insights into the ambiguity and uncertainty involved in decision making. Chapter 6 derives a theoretical framework for understanding everyday decision making using NDM which shares the characteristic of ambiguity and uncertainty. This framework acts as a basis for analysing decision making using CWA (Chapter 7). CWA helps in identifying the constraints that define the boundaries of the system to provide patients with the tools needed to navigate flexibly. For example, the goal of cue recognition becomes a structural component of problem solving which constrains a higher-level goal of Situation Assessment for a decision problem. Decision ladders extract the requirements for supporting different users based on skills, rules and knowledge patients. The strategies analysis highlights the

support needed for various courses of decision making. These allow us to develop decision aids that are flexible enough to support decision ambiguity and uncertainty.

### **11.2.2 Self-care Coupling**

This complexity is addressed using the theoretical framework (Table 6.5) and the AH (Figure 7.1). The theoretical framework shows the various self-care coupling used by the doctors and NDM. Using this coupling AH helps in: (i) mapping the factors like medical history, general health, problem representation, work organisation into the system and (ii) to view the key determinants or drivers needed for typical conditions.

### **11.2.3 Time Stress**

Patient decisions involve time constraints, therefore, in real life it would be hard for the patient to comprehend each and every attribute involved or influencing decision making. CWA analysis helps to address this complexity by allowing us to provide flexibility in the design to support different decision making – rule-based, skill-based or knowledge based.

### **11.2.4 Heterogeneous Perspective**

Each and every individual is different. Patients use different learning styles and have different cognitive and emotional characteristics. Hence, it is hard to code all these into rules or procedures. Application of NDM accommodates this heterogeneous perspective along with the decision ladder and strategies analysis by allowing users to use their experiences in dealing with similar problem, support novice decision makers with sequential process support and provide the tools needed for the experienced to reflect on their health and well-being in making decisions.



### **11.2.5 Social Perspective**

Chapter 5 shows that decision making is influenced by patient's health condition and people. For e.g., patients may be dependent on their partners for meal, hence what to eat involves family members and caregivers. The theoretical framework (Table 6.5) also shows that patients rely on different people in their decision making for information gathering as well as arriving at a decision. This helps us to use AH (Figure 7.2) to define the system boundaries for the tasks and structures specifying the actors involved in the domain along with various processes. SOCA (Figure 7.3) shows how the actors (patients, doctors, nurses) act to fulfil those purposes identified in AH.

## **11.3 Briefly revisiting problems and research implications**

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This section briefly revisits the problems and research implications based on the CISDA process used in this thesis.

### **11.3.1 Understanding Decision Making for Design**

Although real-life experiences were not explored by observing patients due to ethical issues and privacy, this thesis has tried to get an understanding of decision making using 8 focus group studies (Chapter 5 and 6) and a questionnaire study (Chapter 6) to develop case scenarios. Interview studies with 5 doctors were conducted to explore how doctors would support patients in their decision making process during their consultation. Based on these studies, software specification requirements needed for supporting everyday self-care management and decision making is extracted.

### **11.3.2 Systems-based View**

Although this thesis is aimed towards the design and development of software-based decision support system, system level view is needed to address the criteria including: social interaction coupled with different perspectives of the problem, distributed and dynamic system coupled with subsystems, and automation for uncertain quantitative data. This system-based view is provided using CWA analysis (Chapter 7). This thesis demonstrates that the CISDA process can support complex decision making and could be used to map the roles, responsibilities, information, and people. Using system-based view designers can easily capture the decision making process and can translate into human-computer displays.

### **11.3.3 Human Cognition**

Clarke et al (2004), specifies that people use different approaches in decision making so applying theories to decision making helps to create a conceptual model of decision making to examine how individuals make decisions, what options they have (Elwyn 2011) and the factors that affect their decision process (Carayon 2011). For e.g., application of NDM to understand macrocognition, various factors and attributes help in understanding decision making. The theoretical framework (Table 6.5) and the CWA analysis provides the process needed for achieving goals like situation Assessment, diagnosis, generate options and evaluate options.

### **11.3.4 Usability and Usefulness**

CISDA process helps in addressing usability and usefulness through an iterative process with the patients and stakeholders. Interface design phase (Chapter 9) shows an iterative process involved in developing the user interface to address usability concerns. Evaluation phase (Chapter 10) helps to address the usefulness of the prototype through various evaluations: (i)

evaluating with CWA, (ii) with case scenarios, (iii) using verification by doctors, (iv) study with patients, and (v) doctors.

## **11.4 Caveats**

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As this thesis proposes a step-by-step guidelines using the CISDA development process, it is very easy to overstate the approach. This section attempts to rectify any such misunderstanding by providing highlights on the following caveats in this thesis.

### **11.4.1 Strengths/ benefits of the CISDA process**

The CISDA process is mainly aimed at providing development guidance for chronic disease self-care decision making. The strengths of the CISDA approach are:

- Focus on understanding patient experiences and decision making needs.
- Capture a system-level view for modelling the decision making process to extract system features and non-functional requirements.
- Developed from an evidence-based disease management models such as: IPDAS, CCM, MRC and Ottawa.
- An Iterative user-centered approach with built-in checking and auditing of design assumptions.

The CISDA process provides a basis for focusing self-care analysis around patient's concerns and hence increasing the probability of uptake. It establishes a general model that will, inevitably be instantiated in different ways in different decision scenarios.

### **11.4.2 Optional Stages in CISDA**

Each and every phase is designed to meet the requirements needed for developing quality decision support systems (IPDAS, MRC, Ottawa, CCR and Ontario). As shown in the literature review, some of the studies have specified an evidence-based framework in their design but there is little evidence on how the theory formation and modelling is used.

### **11.4.3 CWA vs UML Approaches**

In the beginning of this thesis UML was used to analyse decision making. Due to the complexity involved in decision making, it was difficult to understand: (a) the interaction between people, technology, process and organisation, (b) various strategies used in decision making process, (c) high-level view of the system, means-ends relationship, and (d) competency of people. CWA analysis reveals the components, interactions, cognitive and social requirements for the system using various topological representations (boxes and arrows) and structured definition of the system which can be used to predict performance to represent the domain analysis and potential system architecture mapping tool (Cummings 2006) rather than a bunch of diagrams. Moreover, as CWA's goal is to design information systems that are adaptive for carrying out distinct work domains and tasks, the prototypical attributes play an important role (Fidel and Pejtersen 2004).

Although CWA and UML can be used in requirement analysis to provide input to the design process, they differ in their approaches and aims. UML is mainly directed towards object-oriented design: describing the structural and behavioural properties of the software in order to specify the objects which could support these properties and the architecture in which these objects are related. CWA focuses on human interaction with the system: describing the system in terms of the functions (goals) which the system is intended to support and the

properties of the system which contribute to delivering these functions. One way to view CWA is to see it as providing a bridge between NDM theory involving macrocognition and medical informatics. UML modelling may be faithful to understanding the knowledge required for decision support system, but they have limitations for medical problem solving especially in unanticipated situations (Hajdukiewicz et al 2001). CWA framework places the structural, work domain constraints first, it ensures that the system scope and characteristics have primacy in the analysis when compared to UML approach (Ernst et al., 2006). For example, AH provides a complete system analysis with well-defined system boundaries rather than buried within the process.

#### **11.4.4 CWA to UML - a novel approach**

Chapter 8 shows a methodical, step-by-step, process to integrate Cognitive Work Analysis (CWA) into UML to inform software design. The approach is anchored through an example prototype mobile application intended to help designers in the design of complete systems that preserves flexibility of how those cognitive aspects will be realized. As UML models are developed, designers can feed information and changes back into CWA, fleshing it out with details to refine the system. This translation of the CWA analysis to UML for the design and implementation through a step-by-step process and its illustration through a case study is new to the field.

The study also shows how differently CWA analysis has been coupled in the design and development of decision support system using UML. This coupling knowledge has been gained from the studies where UML have been used in complex systems engineering to facilitate the transition into software development (Doyle and Pennotti 2005). For instance, a general socio-cognitive engineering methodology is described using UML for system specification, implementation, deployment, and testing for the design of human-centred

technology (Sharples et al., 2002). In another study, UML has also been used in the integration of participatory design for the development of socio-technical systems. (Pilemalm et al., 2007).

#### **11.4.5 CISDA and User-Centred Design**

The CISDA process is not a brand new software design process. The basic idea behind CISDA owes much to UCD and STS. CISDA uses an iterative design process by focusing on the ‘people’, ‘work’, and ‘environment’. UCD uses applied research from STS, psychology, engineering, human factors and organisational behaviour. CISDA applies these research areas in the design and development of self-care decision support systems. For instance, decision theory like NDM is applied from psychology and CWA from STS, human factors is used in the development process. CISDA also helps in addressing the ISO 9241 standard requirement for: understanding users, tasks and environments (Chapters 5 and 6); active involvement of users, stakeholders throughout the design and development process (Chapters 5-10); refinement of design using user-centred evaluation (Chapter 9); following an iterative process (Chapters 5-10); address the whole user experience (Chapter 5-6); multidisciplinary skills and perspectives (applying decision theory from psychology and CWA from human factors or ergonomics and organisational behaviour); and evaluate designs (Chapter 10).

CISDA uses UCD as mentioned above to provide a step-by-step process needed for the design and development of decision support systems CISDA draws on the insights developed in disciplines that are concerned with the UCD and STS. In other words, CISDA could be viewed, not as a new design approach, but as a complimentary contribution of these disciplines, integrated in a systematic way that is useful for the development of decision support systems.

#### **11.4.6 CISDA process application in real world**

The worked out example and valuation with patients and stakeholders show that the CISDA process can be applied to provide a comprehensive support for self-care management and decision making for chronic illness such as diabetes or arthritis. In addition to that, the CISDA process provides directions to researchers in different ways:

- (i) As decision making can be influenced by skills, knowledge, experience and information/ cues available to patients, the CISDA process shows how requirements can be extracted through various phases to address this challenge for any domain.
- (ii) The CISDA process shows how requirements can be extracted through the application of descriptive theories like NDM for the design of systems.
- (iii) The CISDA process could provide as a guidelines or starting point for the engineers for developing complex systems
- (iv) The CISDA process addresses the relevant intersection of human factors, systems engineering, and software engineering using a case study that can be applied in similar complex systems.
- (v) The CISDA process demonstrates an approach (and worked out example) for going from a cognitive analysis of the work (or operations) to a design (or prototype) that preserves flexibility of how those cognitive aspects will be realized.

This application should prove useful to a range of practitioners concerned about maintaining a user's cognitive perspective during specification and analysis of a complex system.

#### **11.4.7 Knowledge elicitation techniques**

This thesis methodological perspective is concerned with collecting as much information as needed from the patients and stakeholders for understanding, analysing and representing decision making using focus group studies, questionnaire and interviews. Chapter 4 highlights the methods used in this thesis for collecting data from a conceptual perspective that was found appropriate for the thesis. This does not restrict the designers from applying any knowledge elicitation methods they may find useful (e.g., naturalistic observations, verbal protocols, storyboards, card sorting tasks).

#### **11.4.8 CISDA for the design of a ‘good’ decision aid**

The CISDA process provides a systematic and a methodological process for revealing the software requirements specification needed for supporting everyday self-care decision making. Therefore, success cannot be guaranteed, but it provides a firm foundation for the decision support systems design and to facilitate STS technology and knowledge transfer to practical design through the application of UCD approach.

Overall, the evaluation with doctors on the ‘good’ or ‘bad’ decision in Chapter 10 received a positive opinion that this application would help to assist in consultation process and would be a good decision support system. Elwyn and Miron-Shatz (2010) hypothesize that decisions cannot be measured by their outcomes and offer an alternative means of assessment, which stresses the design process rather than the end results. Bekker (2010) study mentions about the debate on defining a good decision. Barnato (2007) suggests that good decisions in preference-sensitive situations need to include clear information processing about issues contributing to the decision, a good overall comprehension, and a close match between patients’ stated values and the chosen option. Sepucha et al., (2013) specifies that the quality of the decision-making process should help patients to:



- Be clear about what matters most to them for this decision.
- Discuss goals, concerns, and preferences with their healthcare providers.
- Be involved in decision making and adaptations (Sepucha et al., 2013).

Based on these and evaluation for CISDA, the prototype does help in the design process, covers the IPDAS quality criteria for the development of DAs and contributes to meeting the criteria needed for the design of quality decision support system.

#### **11.4.9 Behaviour Change using CISDA**

One of the healthcare interventions goal is to support behaviour change. As the CISDA process consists of a theory formation phase designer can consider using theories for supporting behaviour change like Cognitive Behaviour Therapy.

## Chapter 12 CONCLUSION AND FUTURE WORK

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*“The mere formulation of a problem is far more essential than its solution, which may be merely a matter of mathematical or experimental skills. To raise new questions, new possibilities, to regard old problems from a new angle require creative imagination and marks real advances in science.” Albert Einstein.*

As highlighted at the start of the thesis, very few studies have exactly looked into the concept of addressing the real needs and supporting everyday decision making. This thesis has addressed this need by proposing the CISDA development process for designing self-care decision aids using case studies for needs assessment, theory formation, modelling, integration, interface design and development, and evaluation. This concluding chapter provides a summary of the thesis findings, main contributions and limitations in the research. Important areas for future work are also provided along with final thesis remarks.

### 12.1 Thesis Summary

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This section summarises the thesis highlighting the key findings from each of the chapters as follows:

Chapter 2: Provides literature review of the decision aids: (1) to identify the type of support provided; (2) the design phases, application of theories and models; (3) the development process used; and (4) the gaps in the current literature.

Chapter 3: Shows the Systems Development Template needed for the design of decision aids and proposes CISDA framework for the development based on user-centred design using STS methods.

Chapter 4: Discusses the choice of research methods used in this thesis along with the choice of CWA and UML in this thesis.

Chapter 5: The focus group studies and questionnaire studies provides insights into the day-to-day self-care decision problems faced by patients. The Software Requirements Specifications are document based on the studies.

Chapter 6: Applies NDM decision theory to understand decision making and propose a theoretical framework that can be used for the design and development. The theoretical framework is used for extracting the functional requirements including use cases and class objects for supporting decision making.

Chapter 7: Shows how CWA for modelling and analysing Decision Making using the Software Requirements captured in Chapter 5 and 6. This phase captures the System Features and Performance Requirements for developing the decision aid.

Chapter 9: Helps in providing a step-by-step approach to translate CWA to UML for software design and development.

Chapter 10: This chapter sheds light on the design of user interface using an iterative process by showing the evolution in the user interface design.

Chapter 11: Studies show positive feedback in verifying the decision process, support and validity of the CISDA process for the design and develop self-care decision systems.

## 12.2 Research Questions Revisited

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The focus of this thesis has been on three research questions posed in Chapter 1. This section revisits each research question along with an overview of how the research described in this thesis has helped to understand these areas.

Research Question 1: *How can we describe everyday decision making of CVD patients?*

This question is explored in Chapter 5 and 6. Chapter 5 provides the groundwork needed by highlighting the different decision requirements faced by the patients through focus group studies and questionnaires. The studies show that patients' everyday self-management: (i) comprises of not just treatment compliance but also decision making and (ii) patients need support for managing treatment compliance. For example, for maintaining compliance patients need to adhere to everyday medication routine and make various decisions to do with medication: "What to eat on a daily basis (when taking some medications) (Table 5.5). These decision problems are not well-defined and involve time constraints and uncertainty. As decision making is a complex process in self-management, Chapter 6 formulates a descriptive framework to help in understanding the decision making process based on NDM theory and doctors' approach for supporting patients' decision making to assist in the comprehension of decision making which was evaluated using 20 decision making scenarios collected from patients using a questionnaire study. This descriptive framework helps designers to: (i) understand the attributes and factors that could affect the decision making process (including decision problem, situation assessment, options evaluations, people, past experience and more), and (ii) extract the software requirements specification (functional requirements, use cases and classes) for supporting everyday decision making. This provides guidance to extract the software requirements needed for supporting self-care management

and decision making (Chapter 5 and 6) using focus groups, interviews, questionnaire studies and application of decision making theory.

Research Question 2: *How can we translate the descriptions of CVD patient decision making (Q1) into specifications for software implementation?*

Based on the descriptions of CVD patient decision making (Chapters 5 and 6), Chapter 7 models the decision making process for capturing a system-level view of “how patients make decisions?” using five phases of CWA. CWA provides a systematic representation of self-care decision system and information flow for identifying the means-end relations to examine the path between individual element and system goals. Chapter 7 shows, how CWA can be used in framing different types of decision making and it is argued that patients require different forms of DA to support these different types of decision making. For example, patient’s decision making can be rules, knowledge or skill-based and decision making by a novice may include information seeking behaviour various experienced may use skills and past experiences. These different approaches have been analysed using the five phases of CWA to extract (i) system features based on: social and organisational analysis, work domain, abstraction decomposition hierarchy, strategies, and decision process, and (ii) performance requirements based on: competency analysis, work domain analysis and support for normative and rule-based decisions. These software specification requirements help to capture the system features and performance requirements needed for supporting different types of decision making. Although CWA could be seen as a design method (Bisantz et al., 2003), there is a lack of evidence to directly inform specifications for software implementation. This research question also addresses this gap in translating CWA into software specifications, by demonstrating an approach (and worked out example) for going

from a cognitive analysis of the work (or operations) to a design (or prototype) that preserves flexibility of how those cognitive aspects will be realized.

Research Question 3: *Given the specification developed (in Q2), how can we design decision aids to support everyday self-care decisions?*

Chapter 3 proposes CISDA process by linking relevant chronic disease or decision aid frameworks (IPDAS, MRC, CCM, Ottawa and Ontario framework) and effective software engineering techniques (UCD, HCI, CWA, UML) to facilitate the development of self-care systems. Chapters 5-10 provide details of each of the phases used in CISDA to guide developers in their development process. CISDA gives a concrete methodological perspective for systems engineering and helps to facilitate STS technology and knowledge transfer to practical design through the application of UCD approach. By presenting the CISDA process through a worked example focusing on CVD patients (Chapters 5-10), the goal here is to not only illustrate how the process is applied but also highlight its purpose-specific features. First, CISDA develops and applies a detailed theory of how patients make decisions and uses this to inform design through the extraction of software requirements specification (Chapter 5 and 6). This process not only helps to identify the requirements that potential users might propose, but to also provide a framework in which to consider these requirements. Perhaps a more accurate perspective on this approach might be use-centred design (Norman, 1991). Second, by using CWA to analyse and explore the system as a whole to understand the nature of decision making in that system, CISDA offers a range of views that give different perspectives on how people interact with each other and with different information sources using the 6 CWA phases. Third, the integration phase that helps in translating CWA views to UML views provides a seamless transition from the user-centred perspective to software engineering and the development of a prototype. This means that

rather than having a disjoint between the user requirements analysis and software implementation, there is an auditable path from one to the other.

### **12.3 Study Limitations**

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This thesis is valuable as the CISDA process is proposed using an evidence-based approach and by linking software engineering techniques. However, there are still some limitations for this study.

- a) The CISDA implementation would require companies' willingness to invest in getting people trained understanding and modelling decision making. To overcome this limitation, the future research can look into automatic generation of computer templates.
- b) Observation (Sekaran 2003): although it would have been ideal to observe patients in their day-to-day life making various self-care decisions and 'activities' it was not feasible to carry out observations due to patients' age and intrusiveness involved.
- c) Definitive randomised controlled trial and long term implementation (Campbell et al., 2000): Obviously a more detailed controlled trial and a long term implementation evaluation with user over a period of 3-6 months would be more ideal to evaluate the decision support system developed. This was not pursued due to the following limitations:
  - During the needs assessment study, it was observed that patients currently do not use smart phones and there is no guarantee that people will have the right smart phones (Android).

- If the prototype was to be used as part of the patients' care regime, it would constitute a medical device and would need to be subjected to Medical Device Agency (MDA) approvals. As the focus of this research was on the development of the design approach rather than the specific product it was felt that taking the design to a level which could be presented to MDA for approval did not seem appropriate.
- d) Due to the lack of appropriate self-care decision making knowledge and design approach, this thesis was not in the development of end product but in providing a systematic process for the design and development of decision aids.
- e) Moreover, results of this study should be interpreted with care with regards to small sample size as the analysis involved an interactive human-centered approach for refining concepts mainly through qualitative research. As mentioned in Chapter 4, participants were from British Heart Foundation, local heart groups, and rehabilitation clinics. It is recommended that future studies take into consideration non heart group members to get a wider perspective.

## **12.4 Main Contributions**

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The major contributions resulting from the research detailed in this thesis are:

1. CISDA Process: To address the pressing need for developing individualized decision support system for chronic disease management, this thesis proposes the CISDA process using existing frameworks to break down the complexity in decision making (Chapter 3). This approach fills in some of the criticism faced by current decision aids in providing guidance and step-by-step process using a case study for



implementation. The CISDA process gives a concrete methodological perspective for the development of decision support systems and facilitates decision theory, STS technology and knowledge transfer to practical design and software requirements extraction through the application of UCD approach that is new. The CISDA process addresses the relevant intersection of human factors, systems engineering, and software engineering in a case study. This work has been presented in conferences and some of the phases published in journals as shown in section 1.9 (Chapter 1).

2. Understanding and extracting requirements for supporting everyday decision making: Study on patient's self-management (Chapter 5) shows that self-management involves treatment adherence and decision making. Hence decision making influences compliance in daily self-management and are not separate entities as represented in CCM or Ottawa. The studies in Chapter 5 (section 5.5) shows the extraction of requirements for supporting self-care management. Using this knowledge along with decision theories, and doctor's support in patient's decision making are analysed to propose a descriptive framework to help designers in understanding the features, people and multiple factors involved in the design of decision aids. These phases help to extract the 'functional software requirements' needed for supporting self-care management and decision making. This thesis makes significant contribution to requirements extraction. The descriptive framework provides insights into understanding everyday patients' decision making problem through the comprehension of doctors' and patients' decision making. This work has been presented in international conferences as shown in section 1.9 (Chapter 1).
3. The chapter on Modelling (Chapter 7) shows the analysis of decision making using six phases for gaining a system-level view and for extracting 'system features' and

‘performance requirements’ for supporting different types of decision making. This thesis provides insights into: (i) extracting and synthesizing decision making using CWA to decompose the complex decision making problem through the multi-stage analytical framework, (ii) as decision making can be influenced by skills, knowledge, experience and information/ cues available to patients, it is argued that patients require different forms of DA to support different types of decision making, (iii) application of CWA helps to identify which functions are most likely to be performed in collaboration with other actors (caregivers, doctors or nurses) and which functions might be more problematic for patients, and (iv) the analysis provides insights for DA designers to identify decision process within a population so that appropriate support systems can be developed based on the system features and performance requirements. This work is now published in the Journal of Medical Informatics under the title: “Modelling Elderly Cardiac Patients Decision Making Using Cognitive Work Analysis: Identifying Requirements for Patient Decision Aids”.

4. CWA to UML: Chapter 7 shows how decision making and self-management can be extracted and synthesized into a model using CWA for creating efficient care delivery through the functional perspectives using an in-depth analysis. Systematic translation of CWA to UML is presented along with prototype implementation (Chapter 8). This integration phase is valuable as it not only provides guidelines for integration but it should also prove useful to a range of practitioners concerned about maintaining a user's cognitive perspective during specification of a system and as a source of guidance for human computer interaction practitioners in developing systems. This work is now accepted for publication in the Systems Engineering journal under the

title “A Systematic Approach for Developing Decision Aids: From Cognitive Work Analysis to Prototype Design and Development”.

## 12.5 Future Work

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This thesis has helped to deepen the understanding on how to support patients to self-manage. This is an on- going research space that requires further investigations in a number of different areas.

- a) Activity-centered: Although human-centered design helps to overcome poor design and usability, it is important to understand self-management and decision making activities. This approach should help to reflect the possible range of actions and conditions in which patients make decisions, their constraints and the reasons for activities. Understanding activities would provide greater level of details. This should also help during evaluation for further refining the application.
- Psychology of patients’ decision making: to explore and identify how various theories are applied in patients’ everyday decision making process through compare and contrast method. This knowledge should help the designer to apply different techniques depending on the problem. It would be useful to apply the theories from positive psychology such as Cognitive Behavioural Therapy, behaviour change support systems, and behaviour models that have been promising for the study of user intentions and behaviour change.
- b) This study proposes CISDA process and approach for the design and development of systems. Using this approach, the prototype need to be developed into a commercial

application and evaluated using long-term trial for outcome measurement on usefulness and adoption. By evaluating the prototype, other chronic diseases self-care decision aids can be replicated to prevent and control diseases like obesity and diabetics.

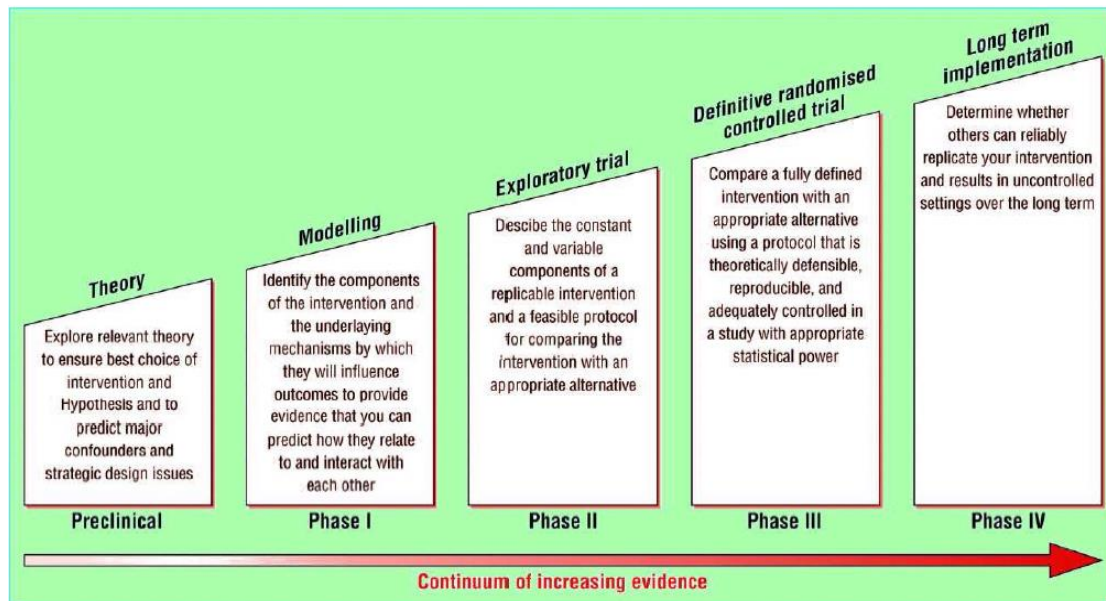
- c) Integrate the prototype with self-monitoring tools for providing a holistic solution. This should not only help patients in providing guidance for self-management but also should help patient and doctors with up to date status information based on vital signs recordings for the detection of acute, episodic events.
- d) The current application does not support any social elements. It would be useful to provide self-care decision aids with social elements for improving self-efficacy and adherence. Also it would provide more support for patients by learning from others experiences and introduction of rewards, gamification, and sharing to increase motivation.
- e) As the CISDA implementation would require companies to invest in getting people trained in UCD and CWA, future research should help to overcome this challenge with the use of computer templates and automatic analysis for providing a formalized approach.
- f) Gather feedback on or testing of the framework by a third party through publication of the CISDA process in the literature, presentation in conferences, arranging workshops and training sessions.

## 12.6 Chapter Summary

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Due to the complexity involved in understanding and analysing everyday decision making, this thesis aims to address this problem by formulating and illustrating the CISDA process through a coherent, structured, integrated design and development process. The CISDA approach is anchored through a case study that involves a methodical, step-by-step development of a prototype mobile application intended to help CVD patients in their daily decision-making. As discussed in Chapter 1, this thesis helps to develop a ‘well-documented development process that IPDAS seeks. This thesis should prove useful to a range of practitioners concerned about: self-care management, decision making, maintaining a user's cognitive perspective during specification and analysis of a complex system.

## Appendix A: MRC Framework



MRC Framework for evaluation of complex interventions (from Campbell et al., 2000)

## Appendix B: Patient Consent

<b>Name of Researcher:</b>  Prof Chris Baber	<b>Name of Department:</b>  Electronic, Electrical and Computer Engineering
<p><b>Research Purpose:</b> We are developing a patient-centric vision to Heart Disease management and treatment by providing people already diagnosed with Cardiovascular Disease with a sound solution for self-management decision making. To help the design process, we first want to talk to people, who have already diagnosed with heart disease, about their experiences, the difficulties they encounter in trying to seek information, and about self-management.</p> <p><b>Research Methods:</b> A number of research methods will be employed; surveys, interviews and focus group discussions. All research participants will be distributed with an individual Informed Consent form, which they must sign, and return to the researcher before the interview can take place. All discussions will be recorded with a digital voice recorder and transcribed.</p> <p><b>Anonymity:</b> All identifiable information of participants in this study would be anonymous.</p> <p><b>Confidentiality:</b> All data will be stored securely either electronically on computer or in hard copy version in the university. As part of the data analysis process, hard copies of the anonymous transcripts (raw data) may be given to the doctoral supervision team and a small number of other research participants to review to ensure that the researcher's analysis has resonance. Hard copies will be returned to the researcher and will not remain in the possession of the research participants.</p> <p><b>Research Dissemination:</b> Data obtained through this research will be reproduced and published in a variety of forms and for a variety of audiences related to the broad nature of the research detailed above (i.e. conferences, peer reviewed journals, articles etc.).</p> <p><b>Risks and discomforts:</b> We appreciate you taking part in this study. This study involves discussing about your health experiences so if you feel uncomfortable you can withdraw from the discussion at any time, without giving a reason.</p> <p><b>Benefit of this study:</b> As this is a long-term development process there is no guarantee that you will directly benefit from taking part in this study. Your participation will researchers develop systems for others who have your condition.</p> <p><b>Queries:</b> <input type="text"/> <input type="text"/></p>	

<b>Title Of Study:</b> Patient Centric Approach for an Integrated, Adaptive, Context Aware Remote Diagnosis and Management of Cardiovascular Diseases.		<b>Date:</b>	
<b>Name of Researcher:</b> Prof Chris Baber, Head of the School		<b>Name of Department:</b> Electronic, Electrical and Computer Engineering	
			<b>Please Initial</b>
1) I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.			
2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.			
3) I agree that the researchers may publish documents or research reports that contain quotations by me but I remain anonymous.			
4) I agree to the interview / focus group / consultation being audio recorded.			
5) I agree that my data gathered in this study may be stored (after it has been anonymised) in the University and may be used for future research.			
6) I agree to take part in the study.			
7) I agree that the researcher can contact me for further study and to evaluate the mobile devices.			Yes      No
<div style="border-top: 1px dashed black; margin-top: 20px;"> <div style="display: flex; justify-content: space-between; margin-top: 10px;"> <span>Name of Participant</span> <span>Date</span> <span>Signature</span> </div> </div> <div style="border-top: 1px dashed black; margin-top: 20px;"> <div style="display: flex; justify-content: space-between; margin-top: 10px;"> <span>Name of Researcher</span> <span>Date</span> <span>Signature</span> </div> </div>			



---

1. *Decision* – what to do about the problem

[illegible]

What role do you prefer in making your decision?	I prefer to share the decision with Wife/ Family/ Doctor/ Nurse I prefer to decide myself after hearing others views. I prefer someone else decides. Who? .....		
Do you have enough support to make a decision?	Yes	No	Not Sure

### 3. Knowledge for making decision:

How do you weigh up the benefits?	By reviewing information      Discussing with Wife/husband Doctor advise      Help from others Nurse      Others:.....		
How do you know the risks associated with the options?	Internet      Library      BHF magazines      GP Nurse      Hospital      Family      Friends Other Patients Others:.....		
Are you clear which benefits matter most to you?	Yes	No	
Are you clear which risks matter most to you?	Yes	No	
Do the risks outweigh the benefits?	Yes	No	
Is your health condition forcing you to make a decision?	Yes	No	
Was there conflict in making a decision?	Yes	No	
Are you satisfied with your decision?	Yes	No	Not sure

### 4. Information Needs: Please tick the right choice

If you wanted to know more information about your decision, where would you find the answers?	Internet      Library      BHF magazines      GP Hospital      Family Friends      Other Patients Experiences Read stories of what mattered most to others			
---	---	--	--	--

	Others: .....
What other factors make the decision difficult?	

*If you have any additional comments you wish to make, please add them here.*

.....  
 .....

*Thank you for your time and corporation.*

## Appendix D: Medicine Information Questionnaire

Dear Participant: Can you please provide us with the details of any ONE medicine you are having at the moment?

Name of the medicine (Choose ONE)	Simvastatin      Atrovastatin      Statin      Aspirin Warfarin Other?.....				
Why do I need this medicine?	Blood thin      Heart Problem      Protection of stents      Heart regulation      Prevent Stroke Lower:    Cholesterol      Blood      Pressure Other? .....				
How frequently is this medicine taken	No. Of times	Once      Twice      Three      Four      Other:			
	Time of the day	Morning      Afternoon      Evening      Night			
What do I do if I miss a dose?	Take next day      Not sure				
Should I take it BEFORE FOOD?	Yes      No				
Can I swallow it with my other medicines?	Yes      No				
Will it interact with other medicines, I am taking?	Yes      No      Not sure If Yes, What might occur?				
What should I avoid while taking this medicine?	Cranberry      Grape fruit      Alcohol: Activities: Herbal remedies:      Others:				
Do you know what side effects you	No side effect      Yes I know the side effects      Don't know      Can't remember				

should be looking  
for to seek help?

Numerous according to information sheet

## Appendix E: User Perception Questionnaire

The purpose of this survey is to examine a Technology Acceptance and usage by the cardiac patients. **The information you provide in this part of the form is confidential.**

### SECTION A: PATIENT BACKGROUND INFORMATION

#### 1) Gender

☐ Male ☐ Female

#### 2) Age

☐ 40-49 ☐ 50-59 ☐ 60-69 ☐ 70-79 ☐ 80-89 ☐ 90-99 ☐ above

#### 3) My ethnic group

Choose one section from A to F, then tick the appropriate box for cultural background.

☐ A: White ☐ B: Mixed Any mixed background  
☐ C: Asian; Asian Scottish; Asian British ☐ D: Black; Black Scottish; Black British  
☐ E: Other ethnic background ☐ F: Prefer not to answer

#### 4) Education Background

☐ Did not graduate from high school ☐ High school graduate  
☐ College Education ☐ University ☐ Graduate School

#### 5) Employment Background

☐ Employed ☐ Retired ☐ Not Employed

#### 6) I came to know about my heart problem.

☐ Less than 6 months ☐ 6 months – 1 year ☐ 2-3 years  
☐ 4-5 years ☐ 5-10 years

**7) Family history of heart disease**

☐ Yes                      ☐ No                      ☐ Not sure

---

**SECTION B: TECHNOLOGY SKILLS****8) Do you have a mobile phone?**

☐ Yes                      ☐ No

**9) How long have you been using mobile phone (years)?**

☐ Not at all    ☐ under 1 year    ☐ 1-5 years    ☐ 6-10 years    ☐ 10+ years

**10) What is/ are the service/s of the Mobile Phone that you use most?**

☐ SMS/ TEXT    ☐ To make calls    ☐ To receive calls    ☐ For emergency

☐ Alerts                      ☐ Calendar                      ☐ Games                      ☐ Internet

☐ Camera                      ☐ None                      ☐ Other (please specify)\_\_\_\_\_

**11) How long have you been using the Internet (years)?**

☐ Not at all    ☐ under 2 years    ☐ 3-4 years    ☐ 5-6 years    ☐ 7 years and more

**12) At present, overall how often do you use the Internet?**

☐ Never use it                      ☐ Less than once a week                      ☐ 2-3 times a week  
☐ Several times a week                      ☐ Everyday                      ☐ Few times a month

**13) What is/ are the service/s of the Internet that you use most?**

☐ E-mail                      ☐ Search information/ research                      ☐ Games                      ☐ Health websites

☐ Social networking    ☐ Others (please specify)\_\_\_\_\_

**14) What is your self-assessment about using the internet (experience)?**

☐ No experience                      ☐ Low                      ☐ Moderate                      ☐ High

**15) Mostly, where do you access the Internet?**

☐ None                      ☐ At my home                      ☐ At the library                      ☐ Work

**16) How do you get the internet connection?**

☐ Broadband                      ☐ Dial-up                      ☐ Wireless                      ☐ Other

\_\_\_\_\_

**17) Do you use any of the following?**

☐ Video games                      ☐ Nintendo DS                      ☐ Wii                      ☐ XBox                      ☐ Others

\_\_\_\_\_

**SECTION C: PERCEIVED USEFULNESS AND PERCEIVED EASE OF USE****18) Using BRAVEHEALTH would improve my health and wellness.**

☐ Yes                      ☐ No                      Not sure ☐

**19) Using BRAVEHEALTH would give me greater control of my health?**

☐ Yes                      ☐ No                      Not sure ☐

**20) Using BRAVEHEALTH makes it easier for me to communicate with physician.**

☐ Yes                      ☐ No                      Not sure ☐

**21) Overall, I find BRAVEHEALTH useful for managing my condition.**

☐ Yes                      ☐ No                      Not sure ☐



**22) Learning to use BRAVEHEALTH would be easy for me.**

☐ Yes      ☐ No      Not sure ☐

**23) I would imagine that most people would learn to use this system very quickly**

☐ Yes      ☐ No      Not sure ☐

**24) I find BRAVEHEALTH to be flexible to interact with.**

☐ Yes      ☐ No      Not sure ☐

**25) I thought there was too much inconsistency in this system**

☐ Yes      ☐ No      Not sure ☐

#### **SECTION D: SECURITY, PRIVACY AND TRUST**

**26) I will use BRAVEHEALTH if I know that my personal information will be captured and stored securely.**

☐ Yes      ☐ No      ☐ Not sure

**27) I will not use BRAVEHEALTH because it might not be secure.**

☐ Yes      ☐ No      ☐ Not sure

**28) I think, I should have the right to control the collection, use and dissemination of my personal information**

☐ Yes      ☐ No      ☐ Not sure

#### **SECTION E: ATTITUDE AND BEHAVIOURAL INTENTION TO USE**

**29) Using BRAVEHEALTH for managing my health would be a:**

☐ VERY GOOD IDEA      ☐ I LIKE THE IDEA      ☐  
DESIRABLE    ☐ IT IS ADVISABLE      ☐ VERY UNDESIRABLE      ☐  
VERY BAD IDEA

**30) Assuming I had access to BRAVEHEALTH, I intend to use it.**

☐ Yes      ☐ No

**31) I will recommend BRAVEHEALTH to others**

☐ Yes      ☐ No

**SECTION F: SOCIAL INFLUENCE, FACILITATING CONDITIONS AND SELF-EFFICACY TOWARD BRAVEHEALTH**

**32) My family would want me to use BRAVEHEALTH:**

☐ Very good idea      ☐ I like the idea      ☐ desirable      ☐ It  
is advisable      ☐ very undesirable      ☐ very bad idea

**33) I would need some guidance or tutorials to use BRAVEHEALTH**

☐ Yes      ☐ No

**34) I felt very confident using the system**

☐ Yes      ☐ No

**35) I needed to learn a lot of things before I could get going with this system**

☐ Yes      ☐ No

*If you have any additional comments you wish to make about BRAVEHEALTH usage, please add them here.*

.....  
.....

*Thank you for your time and corporation. If you have any inquiry regarding this questionnaire survey, please contact Anandhi Dhukaram at AVD016@bham.ac.uk*

## Appendix F: Evaluation Pre-Test

We want to know the profile of people included in our study. Therefore this form asks you for your ethnic origin, gender, education, employment, sexuality and age. **The information you provide in this part of the form is confidential.**

**1) I am:**     ☐ Female                                ☐ Male

**2) Age:**     ☐ 40-49     ☐ 50-59     ☐ 60-69     ☐ 70-79     ☐ 80-89     ☐ 90-99  
☐ above

**3) My Ethnic Group:** Choose one section from A to F, then tick the appropriate box to indicate your cultural background.

<input type="checkbox"/> A: White	<input type="checkbox"/> B: Mixed any mixed background
<input type="checkbox"/> C: Asian; Asian Scottish; Asian British British	<input type="checkbox"/> D: Black; Black Scottish; Black British
<input type="checkbox"/> E: Other ethnic background	<input type="checkbox"/> F: Prefer not to answer

**4) Education Background:**

<input type="checkbox"/> Did not graduate from high school	<input type="checkbox"/> High school graduate
<input type="checkbox"/> College Education	<input type="checkbox"/> Graduate Education

**5) Employment:** ☐ Employed                                ☐ Retired                                ☐ Not Employed

**6) I came to know about the heart problem:**

<input type="checkbox"/> Less than 6 months	<input type="checkbox"/> 6 months – 1 year	<input type="checkbox"/> 2-3 years
<input type="checkbox"/> 4-5 years	<input type="checkbox"/> 5-10 years	

**7) I have a smart phone:**   ☐ Yes     ☐ No

Phone: ☐ Samsung     ☐ Nokia     ☐ HTC     ☐ iPhone     ☐ Nexus                        ☐ Sony  
☐ Blackberry            ☐ Motorola            ☐ Other \_\_\_\_\_

## SCENARIOS – PRE TEST

People with long-term health condition face various day-to-day self-management issues. As you are an expert in self-management, our aim is to understand how you would help Ann and John in the below scenarios to deal with their problems.

SCENARIO ONE: One year ago, Ann, 64 years old, was diagnosed with congestive heart condition. Ann has been managing well. From today morning she is feeling tired. She is not sure of the cause or what to do. What would you suggest to Ann? (please choose 2-3 options and number them based on priority):

- |   |  |   |
|---|--|---|
| <input type="checkbox"/> See the GP       | <input type="checkbox"/> Be active           | <input type="checkbox"/> Due to poor diet   |
| <input type="checkbox"/> Weight problem   | <input type="checkbox"/> Related to emotions | <input type="checkbox"/> Due to medications |
| <input type="checkbox"/> Not enough sleep | <input type="checkbox"/> Other.....          |   |

## Appendix G: Evaluation Scenarios Post-Test

### SECTION A: PERCEIVED USEFULNESS AND PERCEIVED EASE OF USE

**1) SMILE would improve my health and wellness.**

☐ Yes      ☐ No      Not sure ☐

**2) SMILE would give me greater control of my health?**

☐ Yes      ☐ No      Not sure ☐

**3) Overall, I find SMILE useful for managing my condition.**

☐ Yes      ☐ No      Not sure ☐

**4) Learning to use SMILE would be easy for me.**

☐ Yes      ☐ No      Not sure ☐

**5) I would imagine that most people would learn to use this system very quickly**

☐ Yes      ☐ No      Not sure ☐

**6) I thought there was too much inconsistency in this system**

☐ Yes      ☐ No      Not sure ☐

### SECTION C: ATTITUDE AND BEHAVIOURAL INTENTION TO USE

**10) Using SMILE for managing my health would be a:**

☐ VERY GOOD IDEA      ☐ I LIKE THE IDEA      ☐ DESIRABLE  
☐ IT IS ADVISABLE      ☐ VERY UNDESIRABLE      ☐ VERY BAD  
IDEA

**11) Assuming I had access to SMILE, I intend to use it.**

☐ Yes      ☐ No

**12) I will recommend SMILE to others**

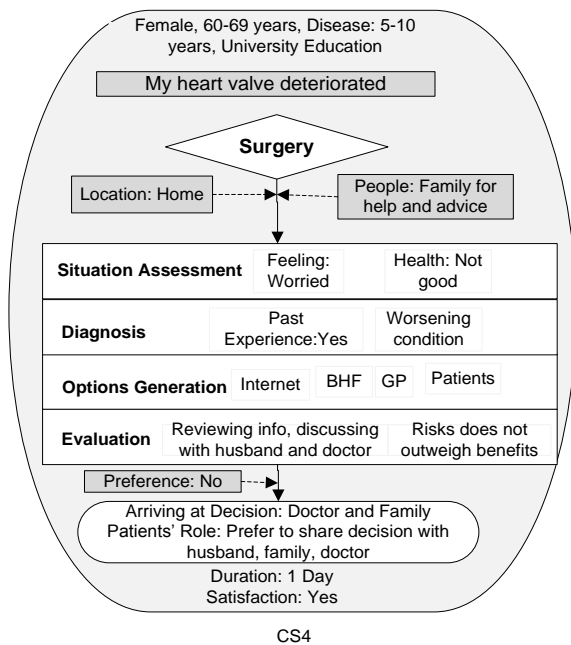
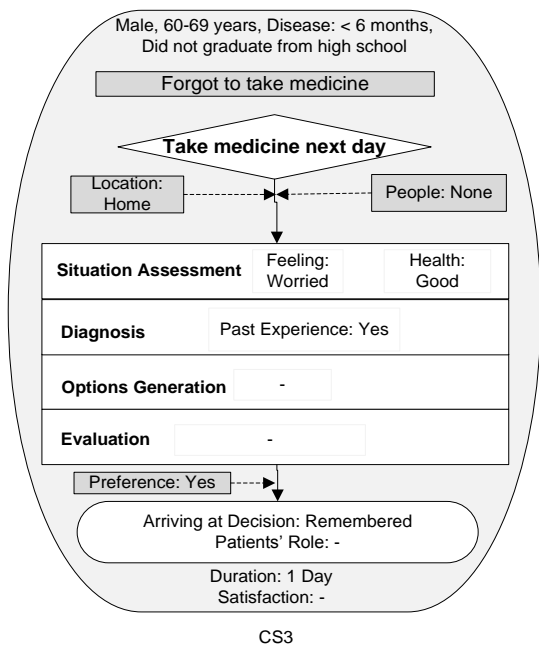
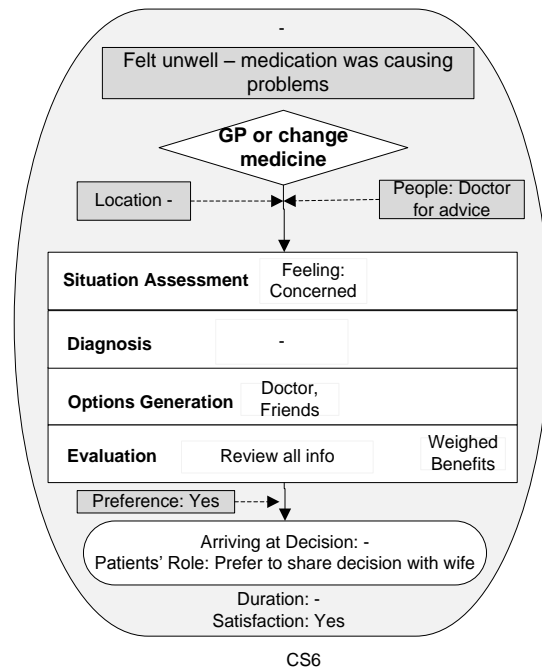
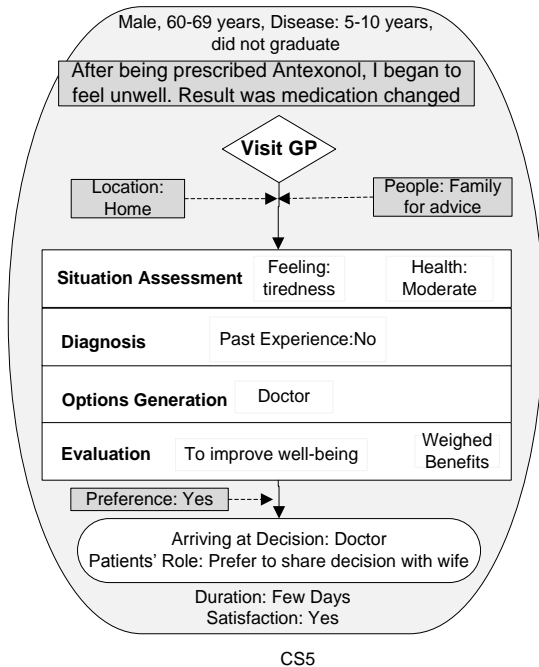
☐ Yes      ☐ No

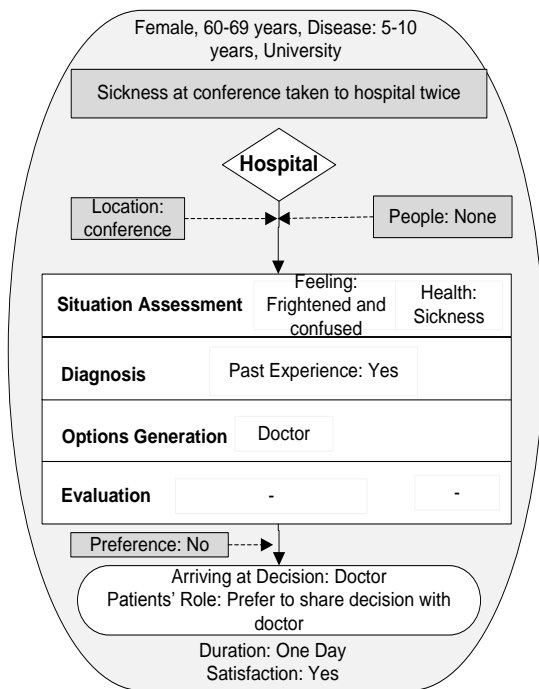
**SECTION D: SOCIAL INFLUENCE, FACILITATING CONDITIONS AND SELF-EFFICACY TOWARD SMILE**

<input type="checkbox"/> VERY GOOD IDEA	<input type="checkbox"/> I LIKE THE IDEA	<input type="checkbox"/>
		DESIRABLE
<input type="checkbox"/> IT IS ADVISABLE	<input type="checkbox"/> VERY UNDESIRABLE	<input type="checkbox"/> VERY BAD IDEA

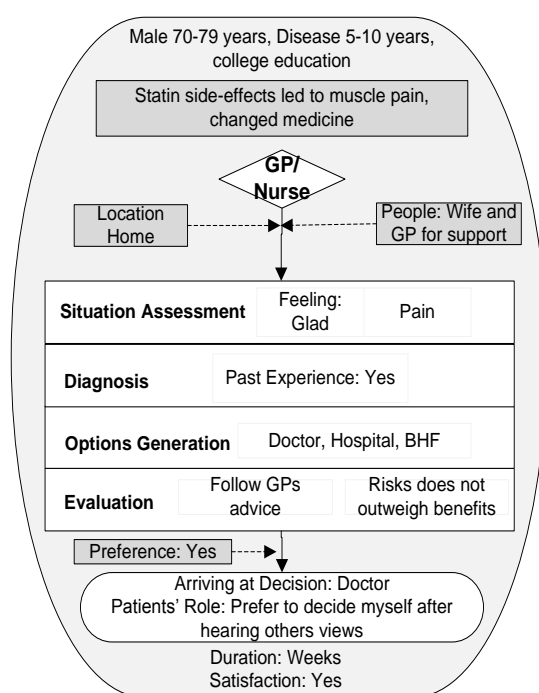
## Appendix H: Patients' Decision Making Scenarios

### Medication Scenarios

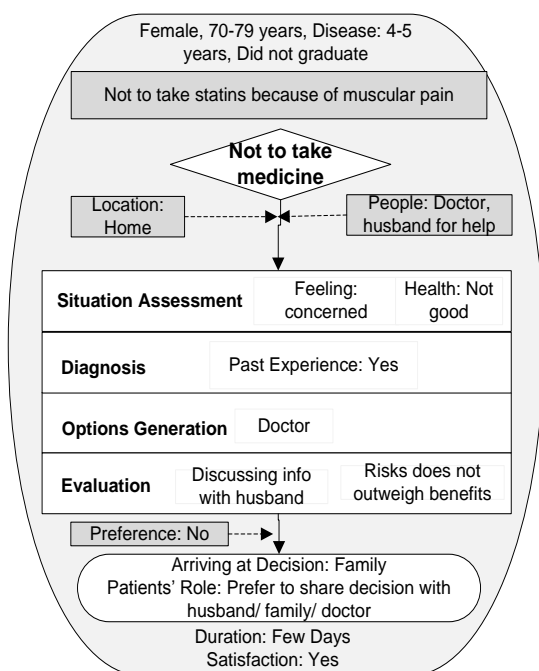




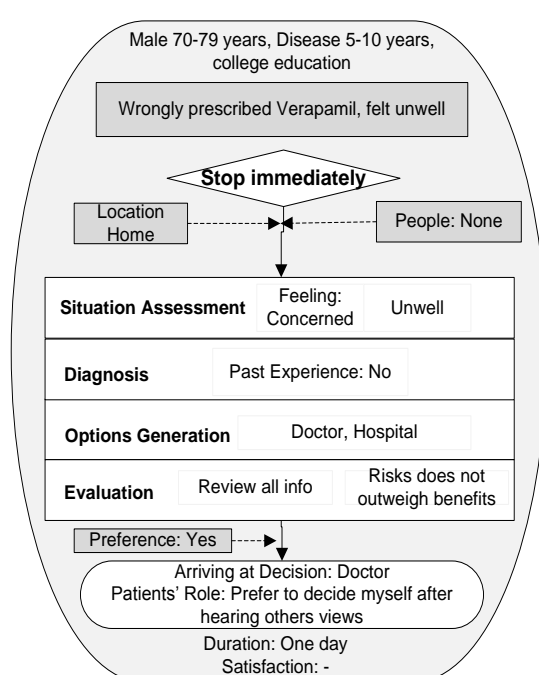
CS7



CS8



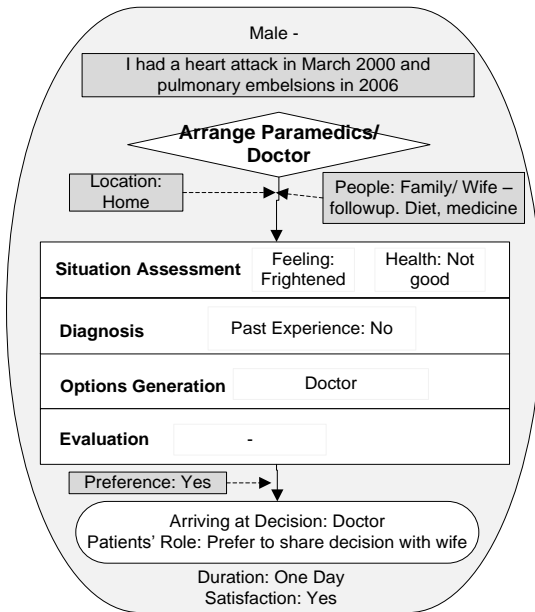
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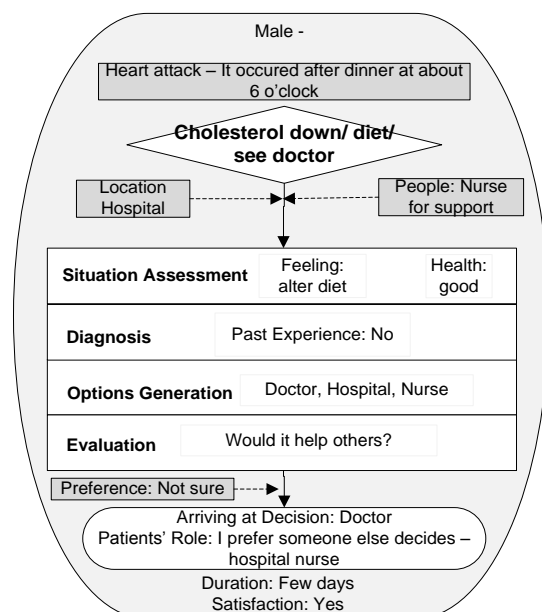
CS10

## Pain Scenarios

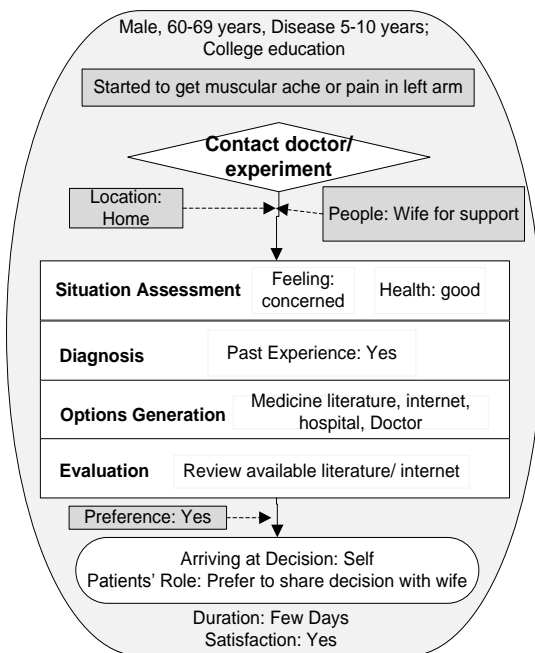




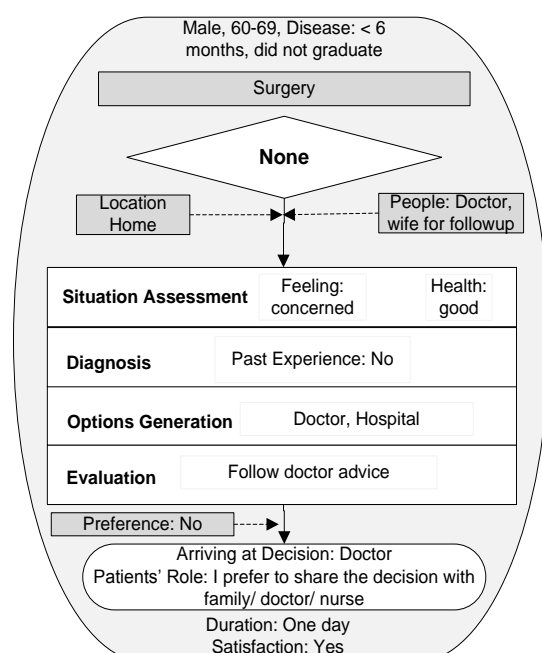
CS13



CS14

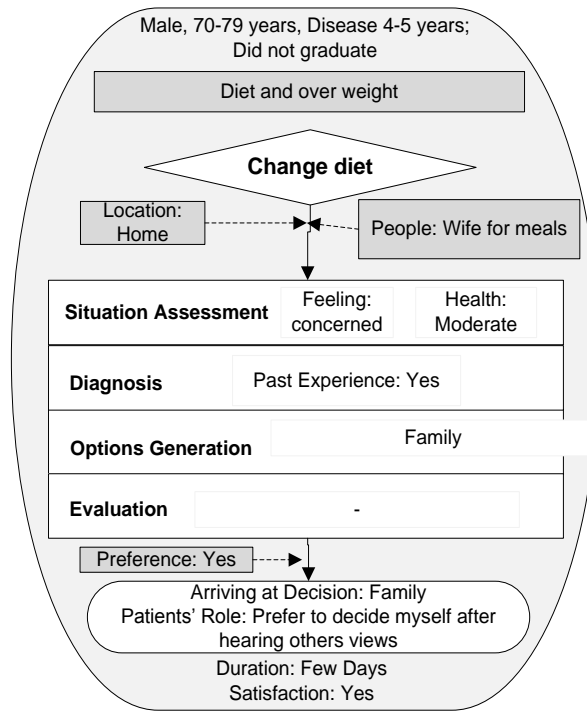


CS15



CS16

## Diet/ Exercise Scenario

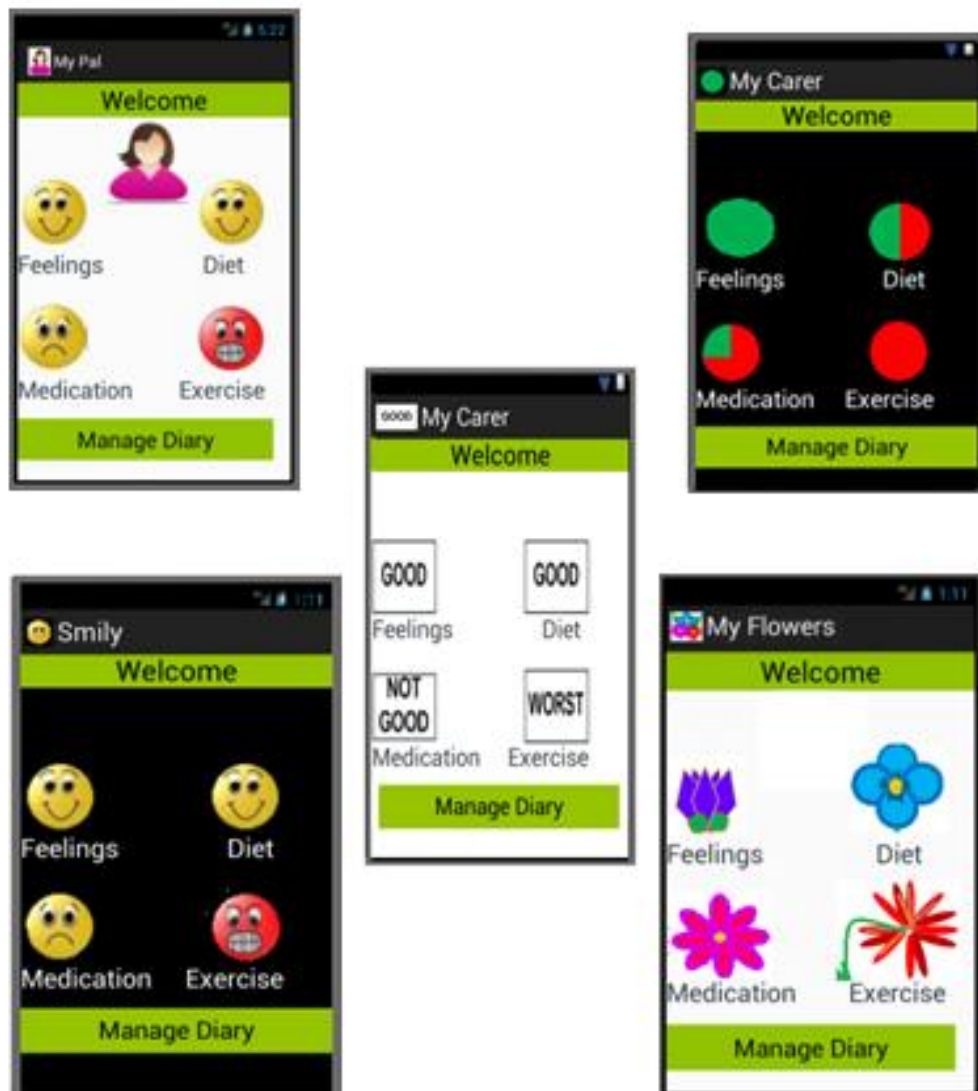


CS20

## Appendix I: Design Study

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### DESIGN STUDY



## MORNING DIARY INPUT SCENARIO - DESIGN 1



What did you like?

What you did not like?

Any other comments?

## MORNING DIARY INPUT SCENARIO - DESIGN 2



What did you like?

What you did not like?

Any other comments?

### MORNING DIARY INPUT SCENARIO - DESIGN 3



What did you like?

What you did not like?

Any other comments?

## MORNING DIARY INPUT SCENARIO - DESIGN 4

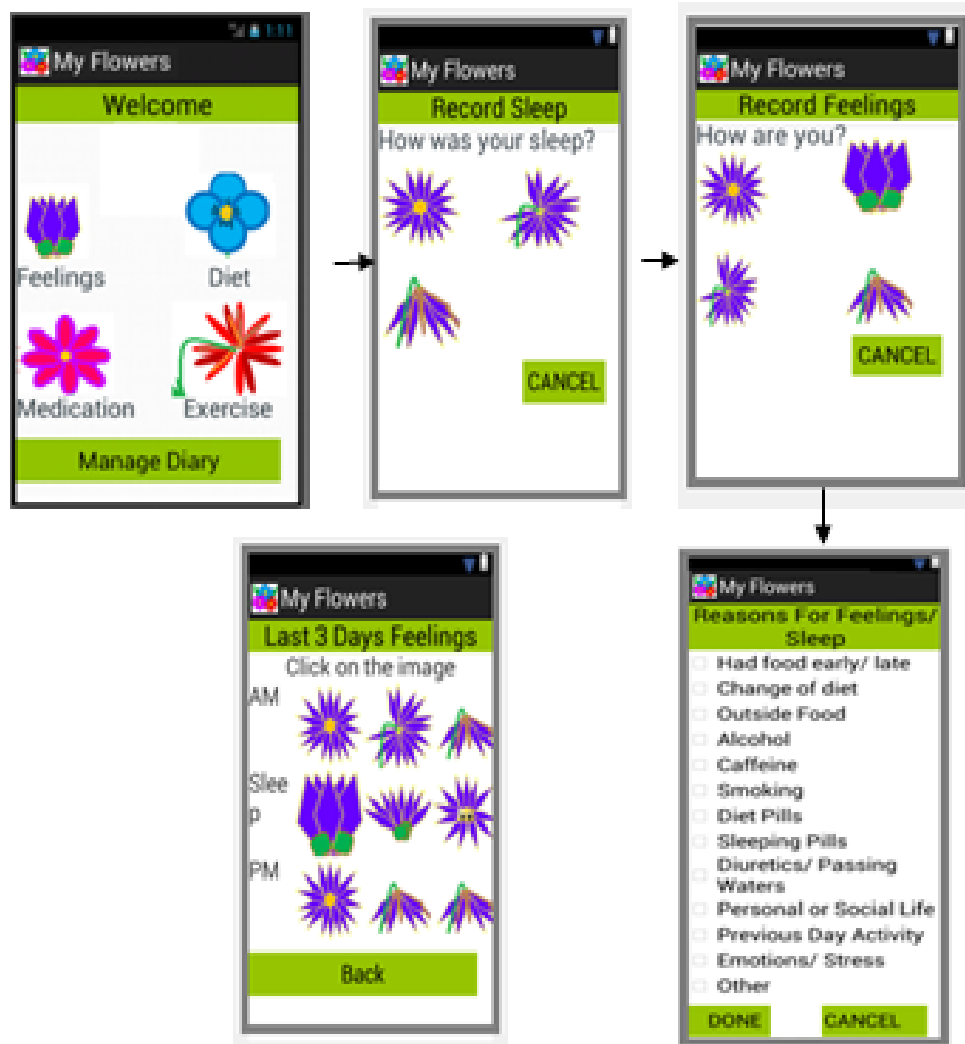


What did you like?

What you did not like?

Any other comments?

## MORNING DIARY INPUT SCENARIO - DESIGN 5



What did you like?

What you did not like?

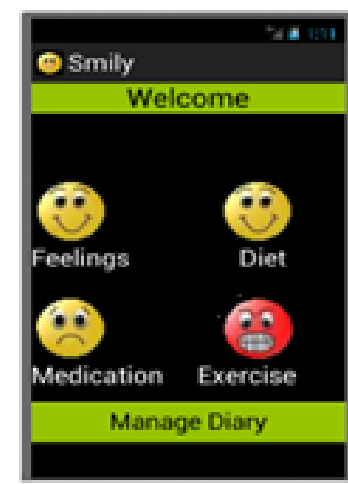
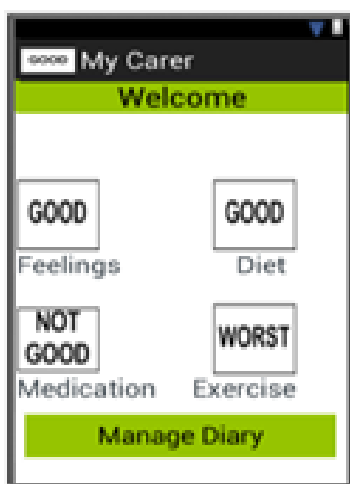
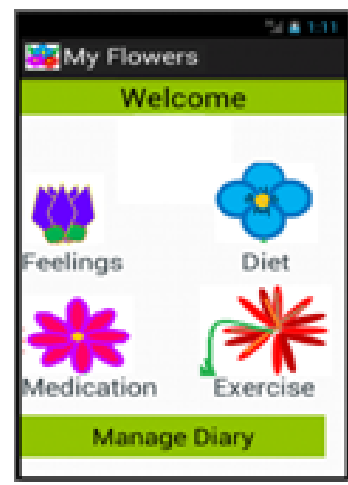
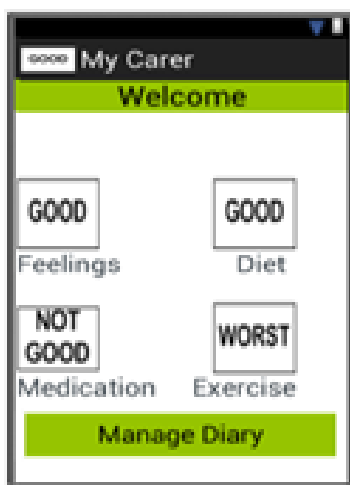
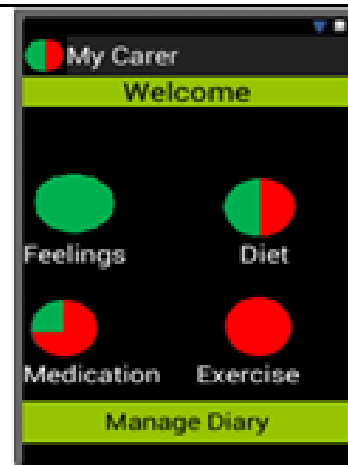
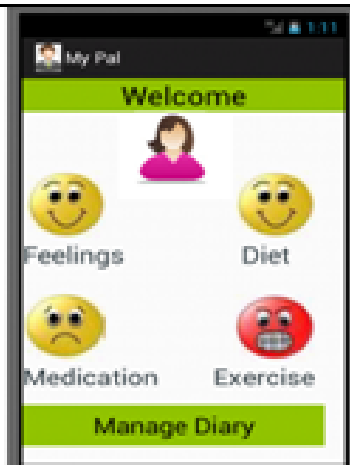
Any other comments?

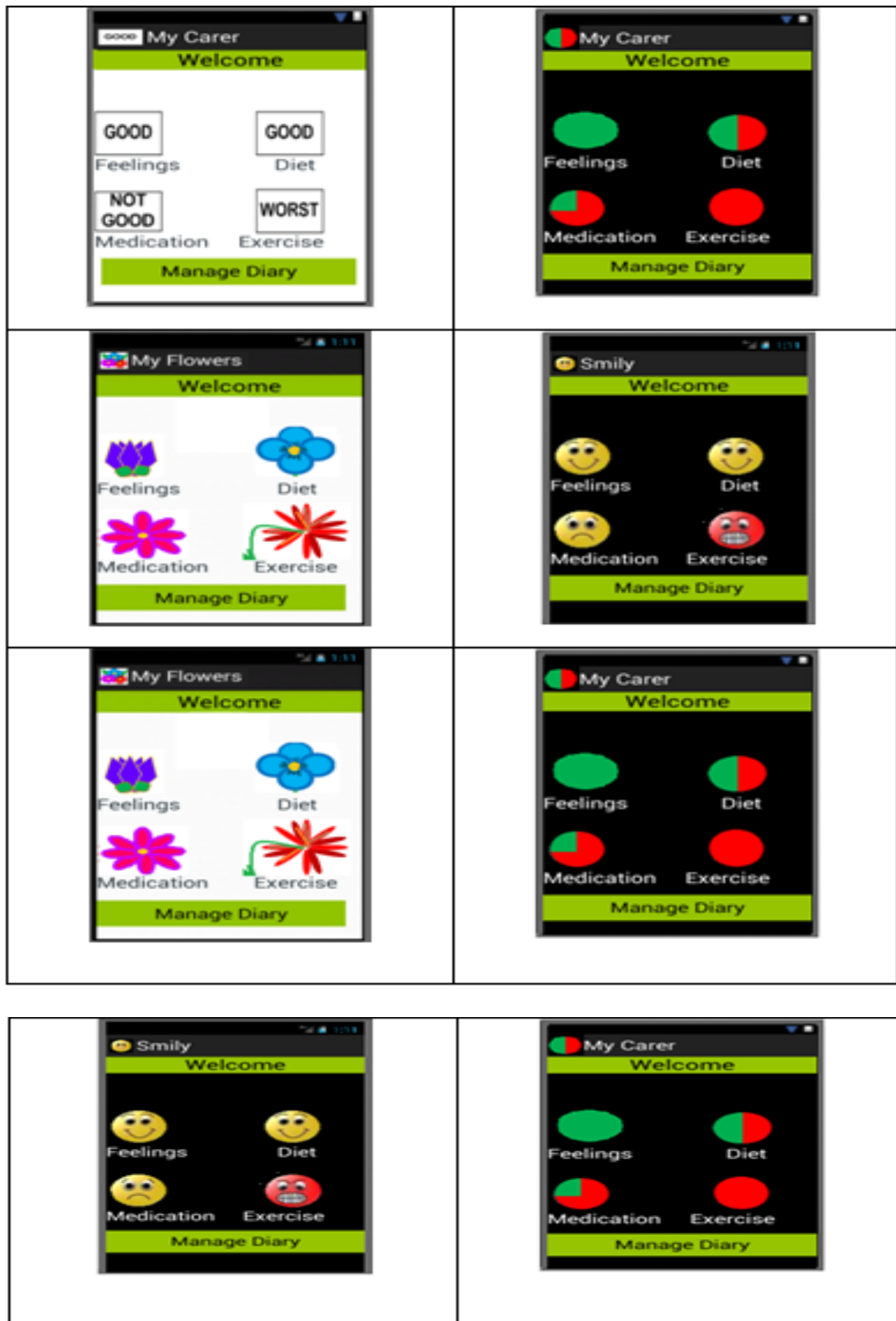




PAIRED COMPARISON: Please tick the design you like the most in each of the pairs.







## YOUR DESIGN

Title?

Colour?

Welcome

Manage Diary

Record Sleep

CANCEL

Record Feelings

CANCEL

Last 3 Days Feelings

Click on the image

AM

Slee

P

PM

Back

Reasons For Feelings/  
Sleep

- ☐ Had food early/ late
- ☐ Change of diet
- ☐ Outside Food
- ☐ Alcohol
- ☐ Caffeine
- ☐ Smoking
- ☐ Diet Pills
- ☐ Sleeping Pills
- ☐ Diuretics/ Passing Waters
- ☐ Personal or Social Life
- ☐ Previous Day Activity
- ☐ Emotions/ Stress
- ☐ Other

DONE

CANCEL

What do you want to change?

Any other comments?

PROBLEM: TIREDNESS



Main Menu

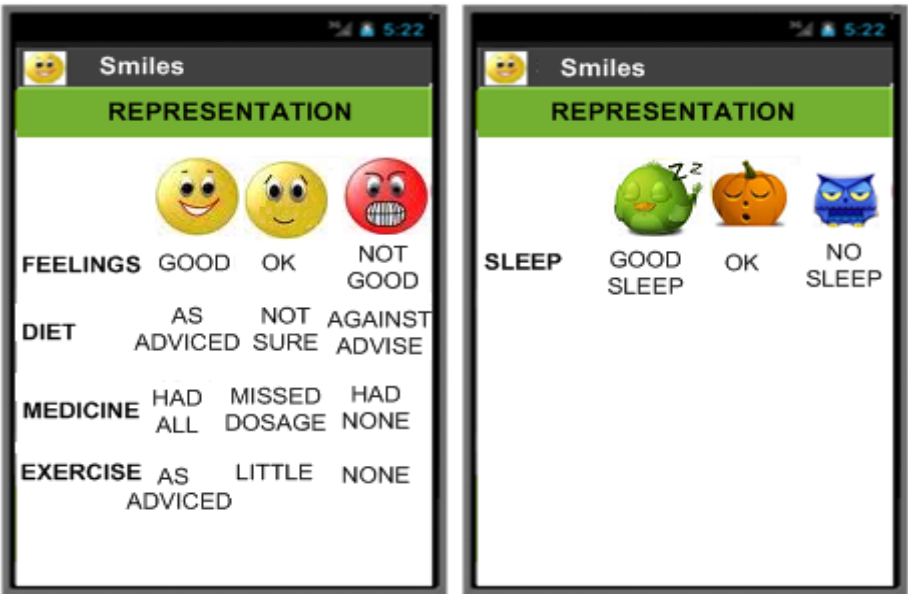
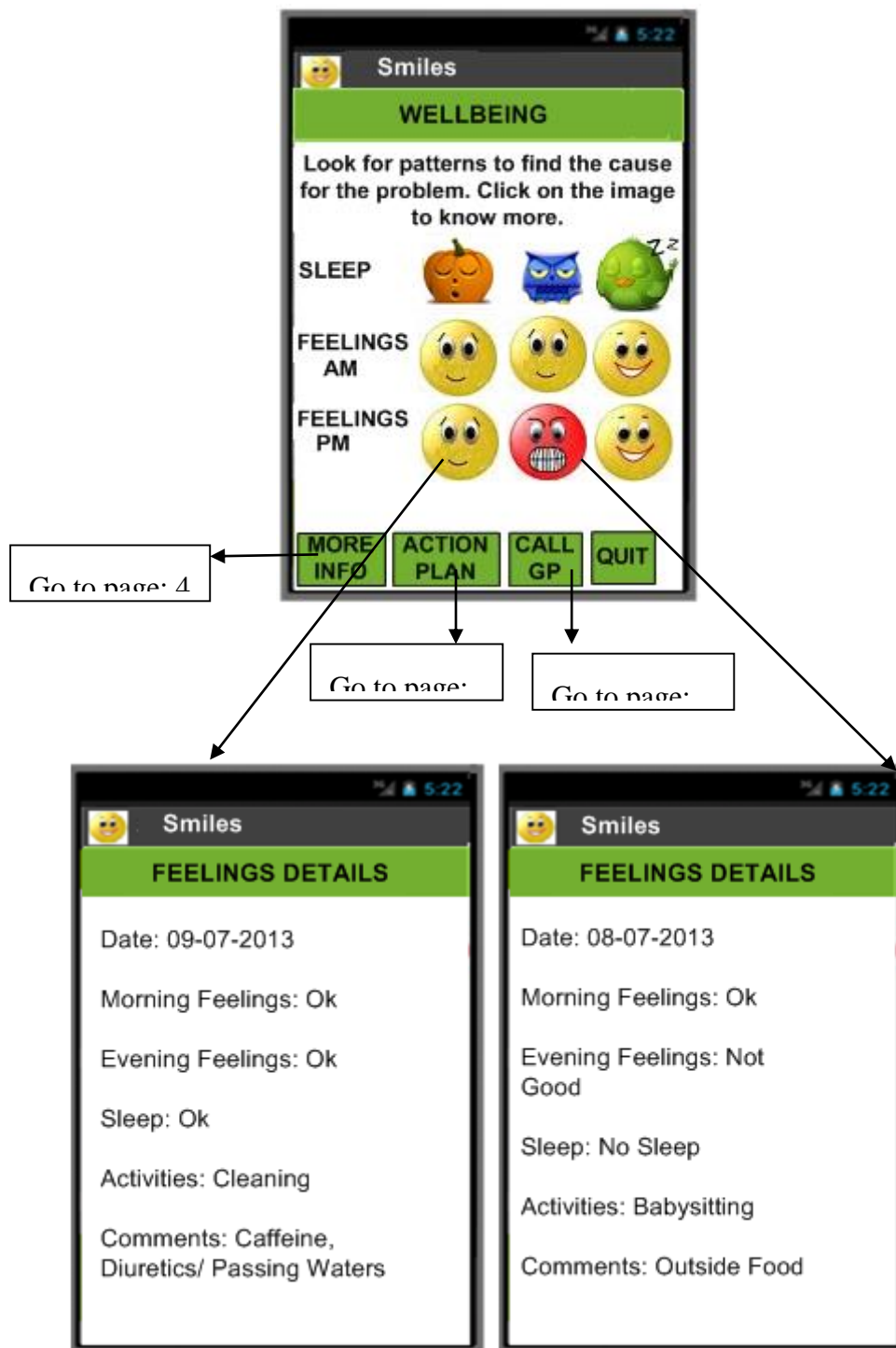


Image Representations

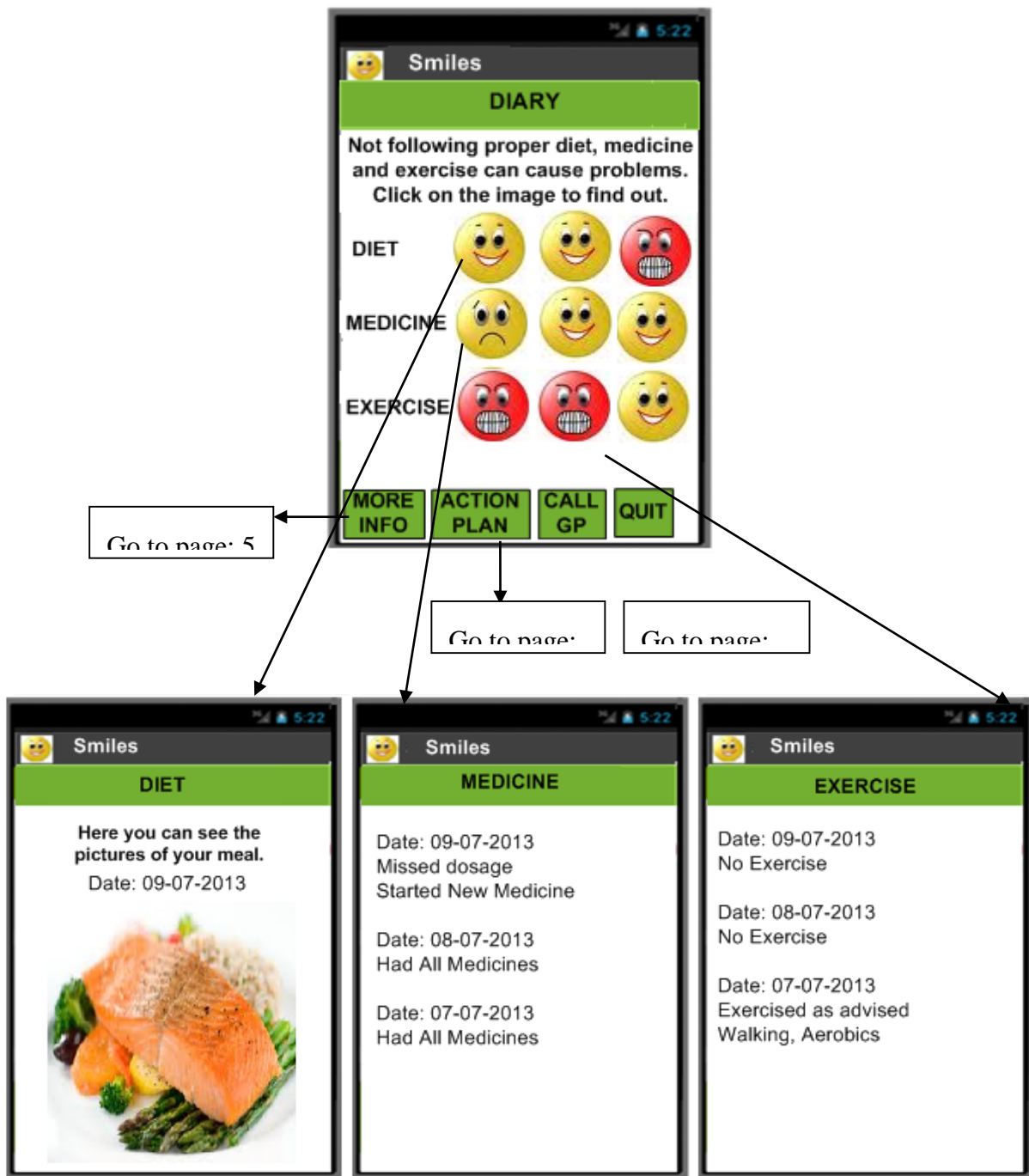
The image shows a mobile application interface. At the top, there is a status bar with the time 5:22. Below it is a header bar with a yellow smiley face icon and the text 'Smiles'. A green bar with the text 'SELF CARE' is below the header. The main content area is white and contains three items, each with a checkbox and a label: 'Feeling Unwell' with an unchecked checkbox, 'Muscle Ache' with an unchecked checkbox, and 'Tiredness' with a checked checkbox (indicated by a black checkmark).

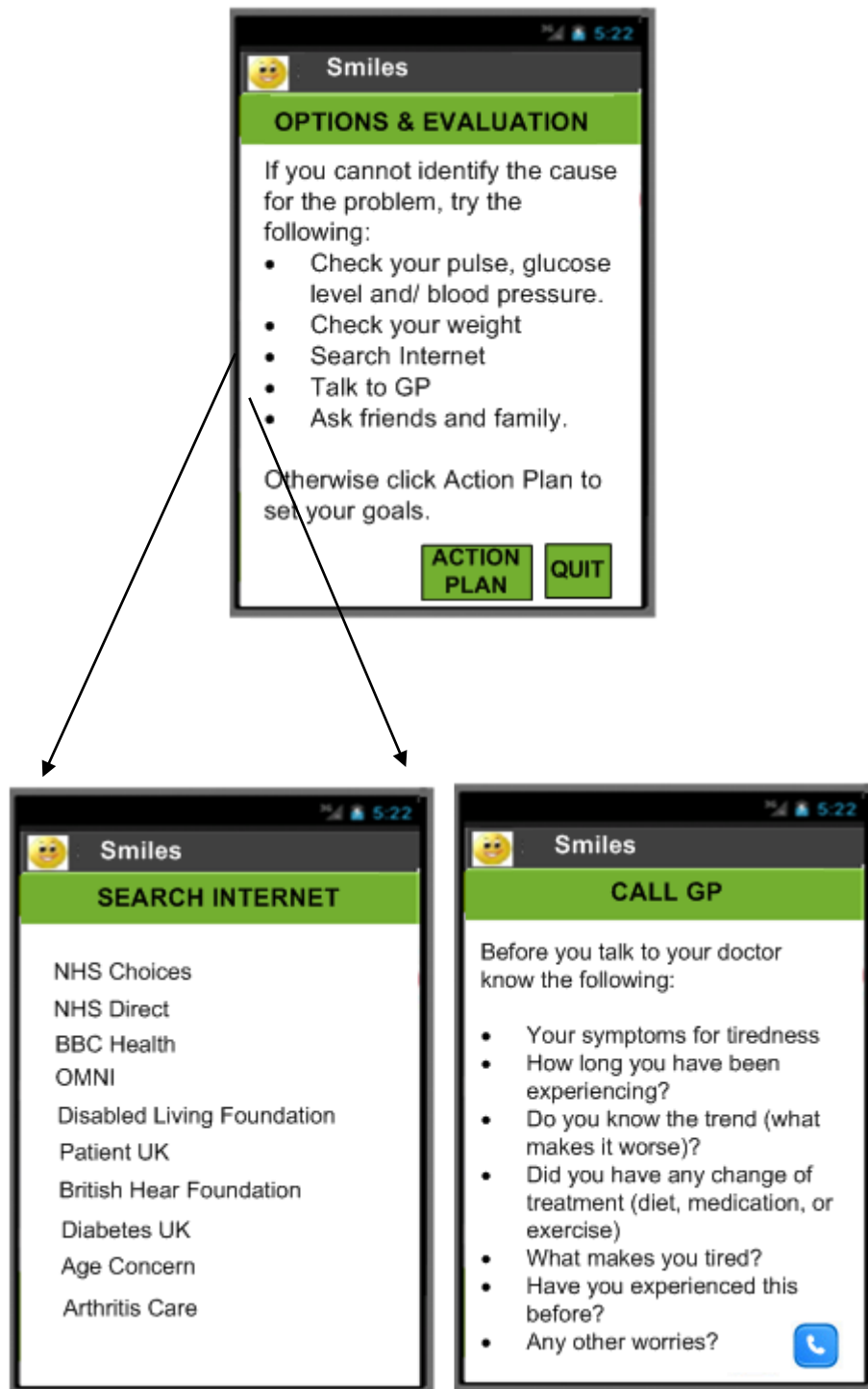
SELF CARE	
<input type="checkbox"/>	Feeling Unwell
<input type="checkbox"/>	Muscle Ache
<input checked="" type="checkbox"/>	Tiredness

Decision Problem









**Smiles**

**ACTION PLAN**

**Possible Cause:**

**Your Goal:**

**What you want to do?:**

**When are you going to do?**

Everyday

**How confident are you?**

☐ Nil ☐ Very Confident

**Do you think you can achieve your goal?** YES NO

**Smiles**

**POSSIBLE CAUSE**

- ☐ Overweight/ thin
- ☐ Illness
- ☐ Physical Activity
- ☐ Poor Sleep
- ☐ Worries/ Stress
- ☐ Emotional
- ☐ Family/ Work Stress
- ☐ Coffee & Tea
- ☐ Alcohol
- ☐ Medication

**Smile**

**GOAL**

- ☐ Manage Weight ?
- ☐ Do Physical Activity ?
- ☐ Improve Sleep ?
- ☐ Reduce Stress ?
- ☐ Control Emotions ?
- ☐ Reduce Coffee & Tea ?
- ☐ Reduce Alcohol ?
- ☐ Take Medications ?

Smiles

**TIPS FOR SLEEP**

- Maintain a regular rest and sleep pattern
- Get out in the fresh air and daylight
- Do not investigate your sleep too much
- Avoid eating before sleep
- Avoid alcohol
- Avoid caffeine
- Avoid smoking
- Avoid sleeping pills
- Stop worrying and relax.

Smiles

**TIPS FOR DIET**

- Ask advice from your doctor about the appropriate diet for you.
- Balance your diet
- Eat less fat
- Eat less sugar
- Eat less salt
- Read food labels

Smiles


**TIPS FOR MEDICINE**

- Ask your doctor, why you need this medicine?
- Know the name of the medicine
- Its side effects and reactions with food or other medicines
- Understand, what happens if you skip the dosage
- When you need to have the medicine, its better if you can associate with your meal times
- Use a pill box to manage your medication

Smiles

**TIPS FOR PHYSICAL ACTIVITY**

- Ask your doctor or nurse, why you need to do exercise?
- Know what exercises you can do
- Follow a regular routine for your exercise
- Join your local community group or exercise classes
- Know your limits

 Smile

SUMMARY

Problem: Tiredness

Possible Cause:

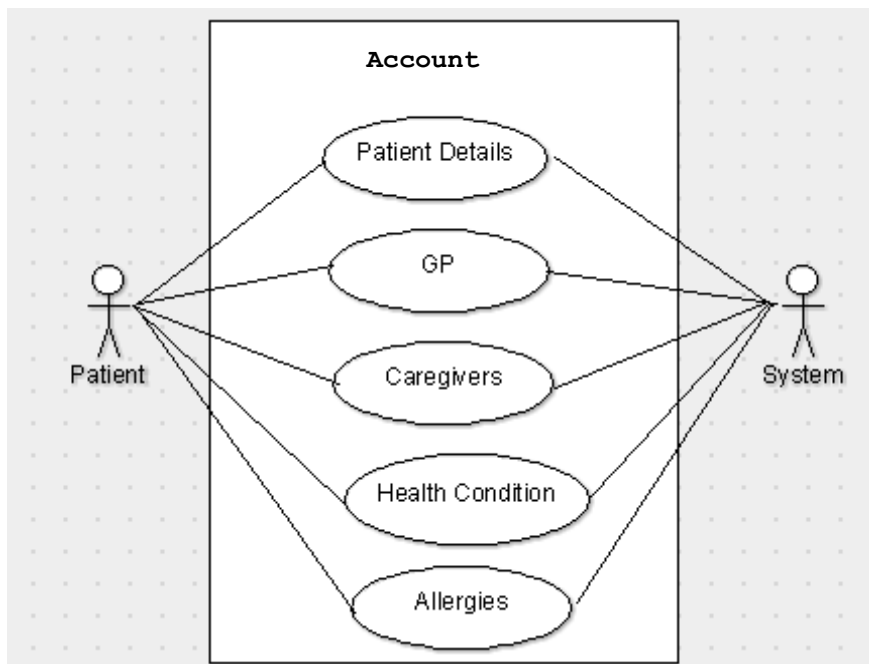
Your Goal:

What you want to do:

When are you going to do:

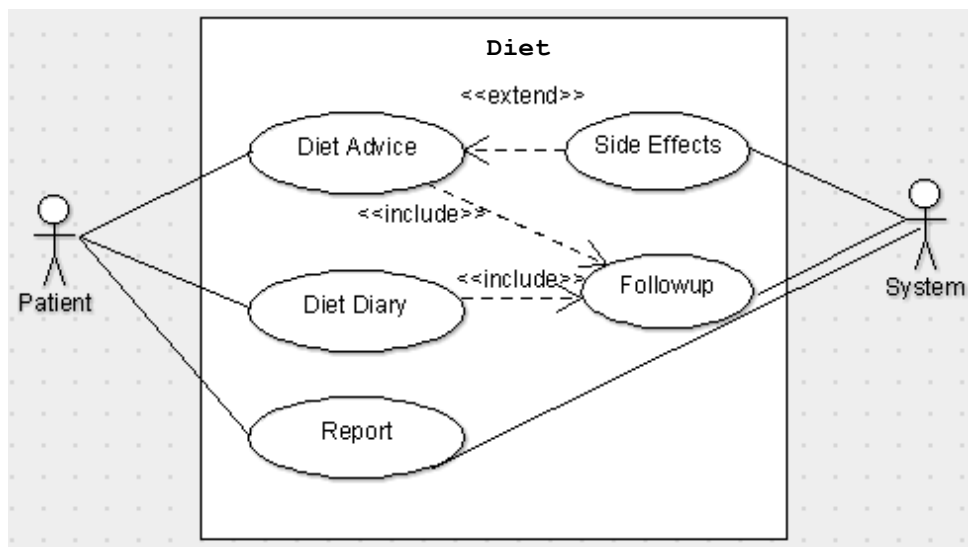
Confidence level:

## Appendix K: Use Case Diagrams

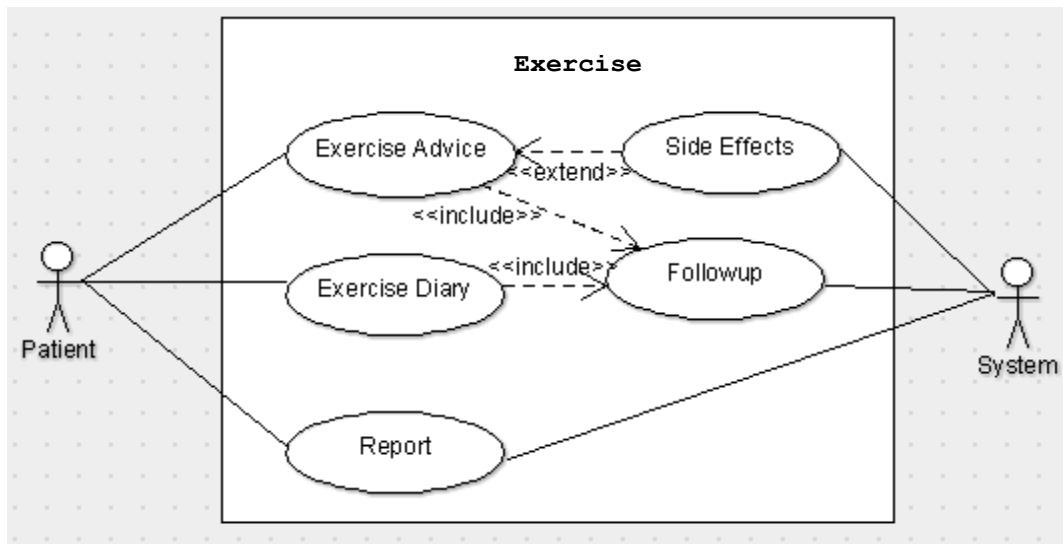


Account Use Case

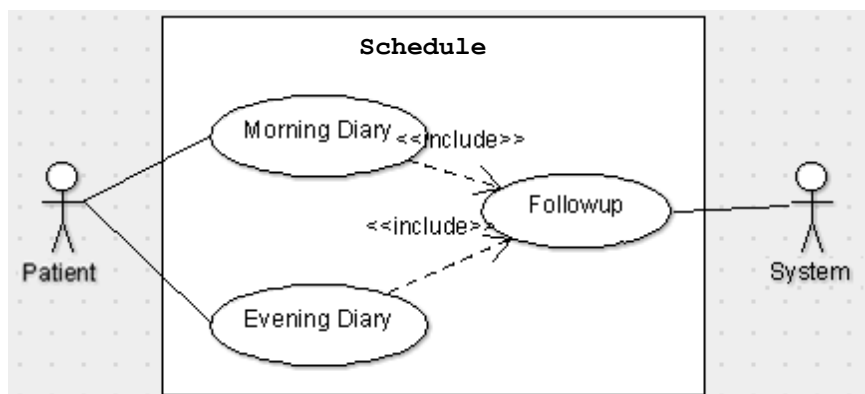
### Diary Management



Diet Use Case Diagram

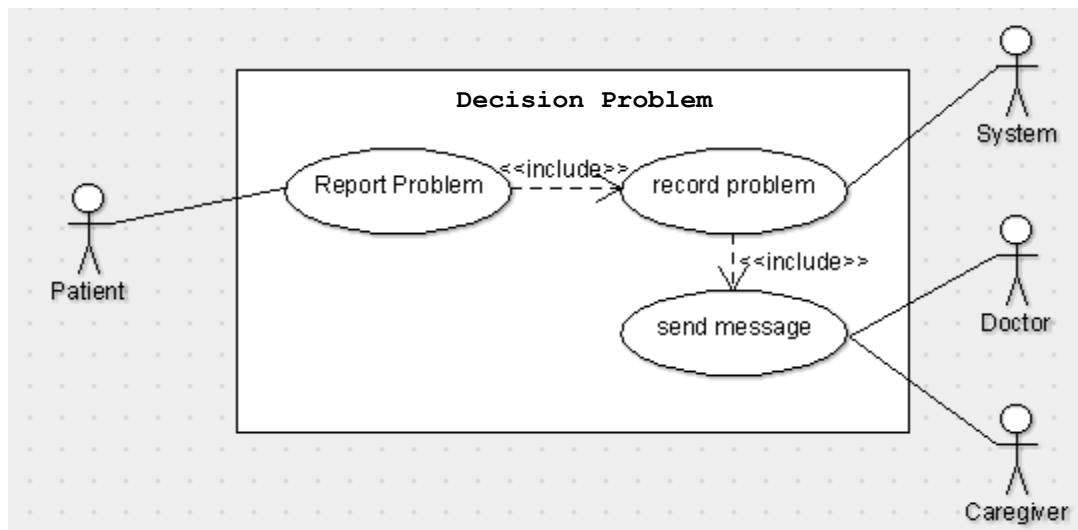


Exercise Use Case Diagram

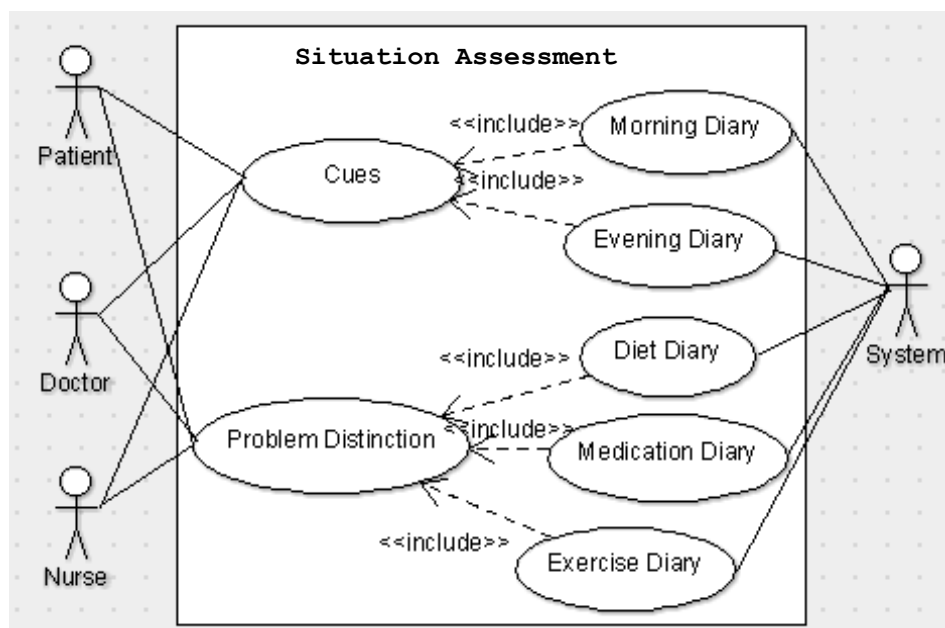


Schedule Use Case Diagram

## Use Case Diagrams for Decision Analysis

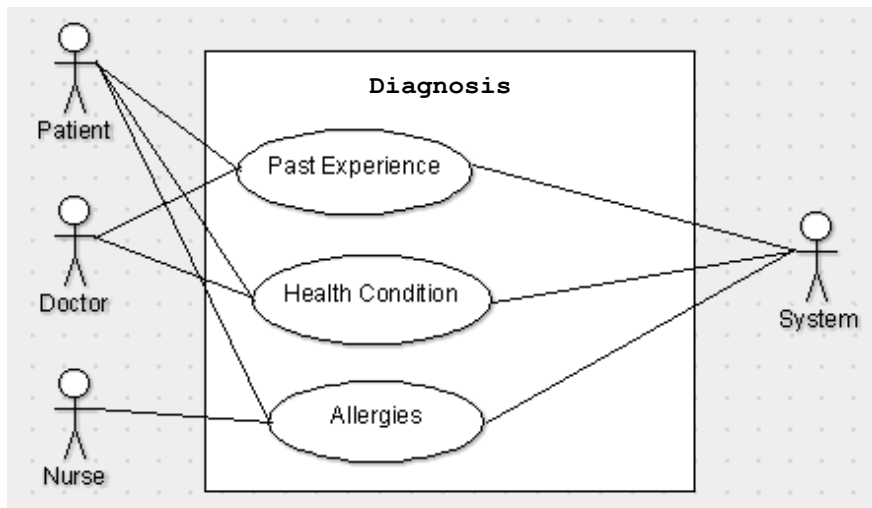


Decision Problem Use Case Diagram

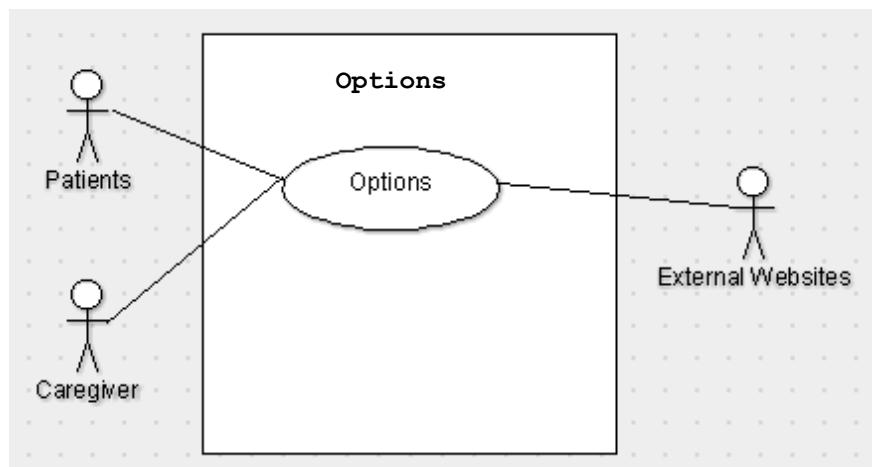


Situation Assessment Use Case

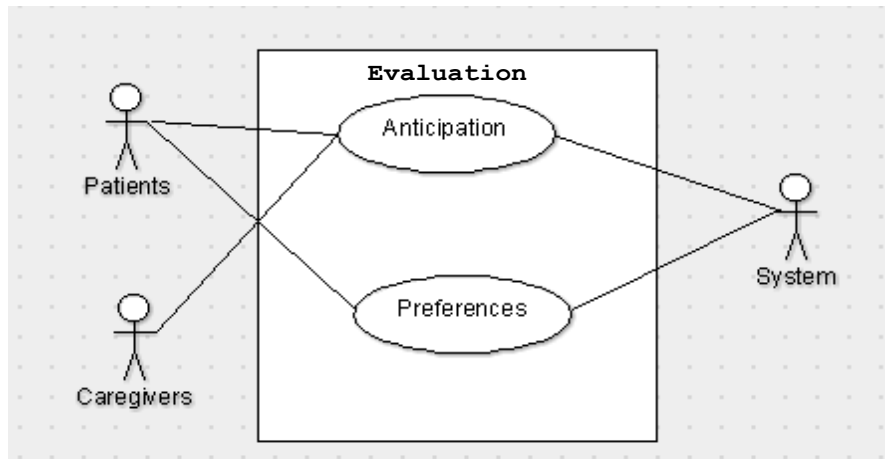




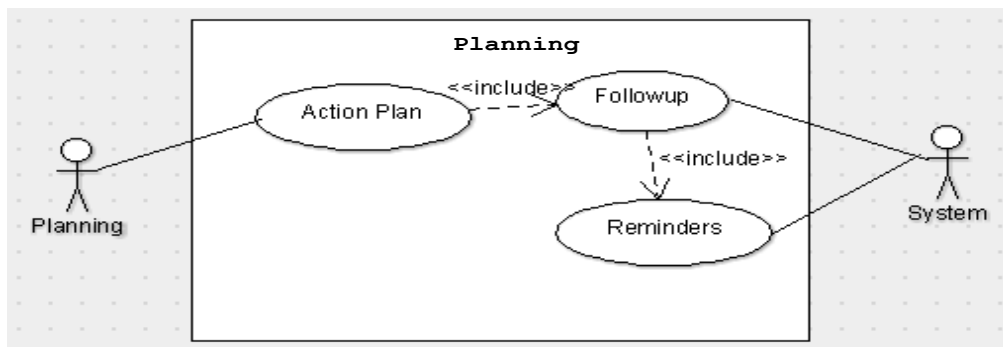
Diagnosis Use Case



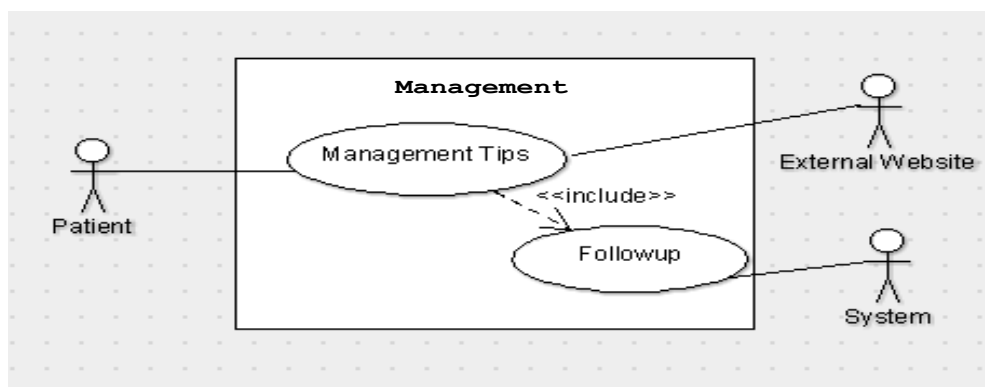
Options Use Case



Evaluation Use Case

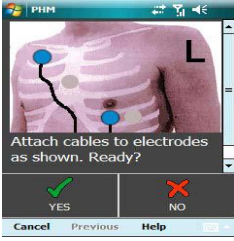
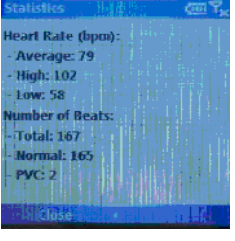


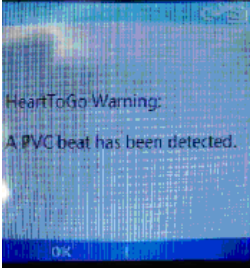

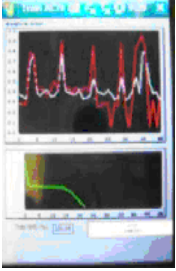


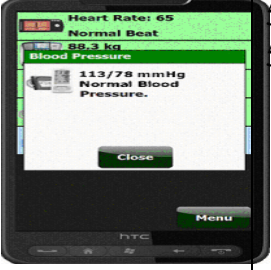

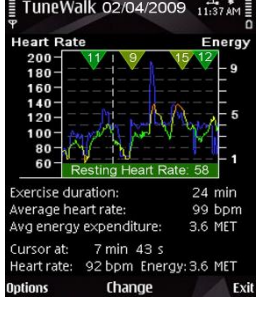



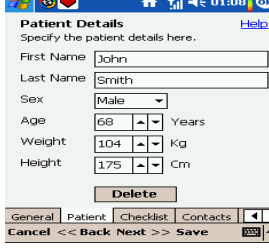


Planning Use Case



Management Use Case

## Appendix L: Mobile Apps

4 5		4 6		4 7		4 8	
4 9		5 0		5 1		5 2	
5 3		5 4		5 5		5 6	
5 7	 Figure 5: Detailed exercise instructions	5 8	 Figure 6: Feedback reported to health professionals	5 9		6 0	

## Appendix M: Excel Spreadsheet

DISPLAY	TEXT >12	TEXT <12	COLOUR	SCROLL L BARS	GRAPHS	ICOM SYMBOL	INPUT TEXTBOX	LIST OF ITEMS	VIDEO S	BACK GROUP INFO	HEALTH METER	TRAFFIC LIGHTS	COSTS	Q&A SCREEN	Q&A DIFF SCREEN	HELP OPTION MENU	DROPPED	CONTROL PANEL	CHECKBOX	WARNING	IMAGES	MULTI- LINE TEXTBOX	SUBMIT BUTTON
1	0	1	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	1	0	0	0	0	1
2	0	1	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	1	1
3	0	0	1	0	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
4	1	0	1	1	0	1	0	1	0	0	0	0	0	0	0	0	1	0	0	1	0	0	1
5	1	1	1	1	0	1	0	0	0	0	1	0	0	1	0	0	0	0	0	0	0	0	1
6	0	1	1	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
7	0	1	1	0	1	0	0	1	0	0	0	0	0	1	0	0	0	0	0	0	1	0	0
8	1	0	0	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
9	1	0	1	0	0	1	1	0	0	0	0	0	0	0	0	1	0	1	0	0	0	0	1
10	1	0	1	0	0	0	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0
11	1	0	1	1	0	1	1	0	0	0	0	0	0	0	0	0	1	0	1	0	0	0	0
12	0	1	1	0	1	1	1	0	1	0	0	1	0	0	0	0	0	0	0	0	1	0	1
13	0	1	0	1	0	1	0	0	1	0	1	0	0	0	1	0	0	0	0	0	1	0	0
14	1	0	1	0	0	1	1	0	1	0	1	0	0	0	0	0	1	0	0	0	0	0	0
15	1	0	1	0	0	1	1	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	1
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17	1	0	1	0	1	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
18	0	1	1	1	0	1	0	0	1	0	0	0	0	0	0	0	0	1	0	0	0	0	1
19	1	0	1	0	0	1	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1
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22	1	0	1	0	1	1	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
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32	1	0	0	0	1	0	0	0	0	0	0	1	0	0	0	0	0	0	0	0	0	0	0
33	1	0	1	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1
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## Appendix N: Doctor's Feedback

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### Pre Test Hypothetical Decision Scenario

SCENARIO ONE: One year ago, Ann, 64 years old, was diagnosed with congestive heart condition. Ann has been managing well. From today morning she is feeling tired. She is not sure of the cause or what to do. What would you suggest to Ann? (please choose 2-3 options and number them based on priority):

- |   |  |   |
|---|--|---|
| <input type="checkbox"/> See the GP       | <input type="checkbox"/> Be active           | <input type="checkbox"/> Due to poor diet   |
| <input type="checkbox"/> Weight problem   | <input type="checkbox"/> Related to emotions | <input type="checkbox"/> Due to medications |
| <input type="checkbox"/> Not enough sleep | <input type="checkbox"/> Other .....         |   |

### Post Test Hypothetical Decision Scenario

SCENARIO ONE: One year ago, Ann, 64 years old, was diagnosed with congestive heart condition. Ann has been managing well. From today morning she is feeling tired. She is not sure of the cause or what to do. What would you suggest to Ann? (please choose 2-3 options and number them based on priority):

- |   |  |   |
|---|--|---|
| <input type="checkbox"/> See the GP       | <input type="checkbox"/> Be active           | <input type="checkbox"/> Due to poor diet   |
| <input type="checkbox"/> Weight problem   | <input type="checkbox"/> Related to emotions | <input type="checkbox"/> Due to medications |
| <input type="checkbox"/> Not enough sleep | <input type="checkbox"/> Other .....         |   |

### Assessing Patient's Decision Making

	Completely Disagree	Somewhat Disagree	Slightly Agree	Mostly Agree	Completely Agree	Comments
Be active						
Not enough sleep						
Due to medications						
See GP						

### Questionnaire for Decision Support

1. How many years of experience do you have? \_\_\_\_\_

2. Please respond to the following.

	Completely Disagree	Somewhat Disagree	Slightly Agree	Mostly Agree	Completely Agree
<b>Usefulness to Patient's</b>					
It would help patient's in their decision making process					
It would provide a useful support for patient					
It would help patients to better self-manage					
<b>In Practice Planning</b>					
It would assist in consultation					

It would help me to quickly review the patient's status					
It would help me to quickly review the patient's trends					
It would assist in my consultation with patients					
It would assist me to provide patient education					
It would improve the quality of consultation time with the patient					
<b>Decision Support</b>					
Decision making process is simple to follow					
Options and values are easy to evaluate					
Reduce decisional conflict					
Would improve patient decision making					
Are compatible with how I think patients should make decisions with regards to the decision problem like "tiredness" and general problems					
I would recommend it to patients					
Overall, I am satisfied with the decision support					

Would improve the match between the chosen option and the features that matter most to the informed patient.					
Would make patients anxious					
Would help patients to be more involved in healthcare					
Comments:					

#### Appendix O: Professional's Feedback

##### Questionnaire for Design Approach

1. Your speciality: IT/Systems Engineering      Psychology      Both      Other:  
\_\_\_\_\_

2. How many years of experience do you have in your field? \_\_\_\_\_

3. Experienced\ knowledgeable in: (Tick all that is applicable)

<input type="checkbox"/>	Decision Making	<input type="checkbox"/>	Education/research
<input type="checkbox"/>	Decision Theories	<input type="checkbox"/>	Patient/ User-centred Approaches
<input type="checkbox"/>	Human Factors/ Ergonomics	<input type="checkbox"/>	Healthcare Technologies
<input type="checkbox"/>	Systems Engineering	<input type="checkbox"/>	Design of Systems
<input type="checkbox"/>	Cognitive Engineering	<input type="checkbox"/>	Others

4. Please respond to the following.



	Completely Disagree	Somewhat Disagree	Slightly Agree	Mostly Agree	Completely Agree
<b>Usefulness of Design Approach</b>					
The design approach seems to be well defined with various stages					
The design framework provides a patient-centric approach					
Needs assessment would help in capturing patient's needs					
Application of decision making theory would be useful in understanding self-management decision making					
Human factor analysis would help in modelling decision making					
Human factor would help to understand decision making from various viewpoints.					
Integration of Human factor to software design would be useful to assist developers					
Overall the approach seems to be useful for supporting decision making					
<b>In Practice</b>					
I would use the approach for similar applications					
I would need some training to adapt this approach					



## Appendix P: Literature Review – Decision Support Design

Paper	Purpose	Format	Self-care	PDA Development	Framework	Needs	Theory	Application of theory to describe decision making	Natural Decision Making Process	Decision Process	Step-by-step decision process	Courses of Action	Interface	Integrate	Context	Organization	Evaluation	DM Support
Dickson et al., (2014)	Heart Failure Self-care	Face to Face	✓	Individual, Environment, social, behaviour			Naturalistic Decision Making (NDM)	NDM features needed for developing support						✓			✓	Skill building
Catherine et al., (2014)	Diabetes Self Care	Web-based	✓	User-centered design	Health Information Model	✓	Self-efficacy			Cognitive Task Analysis							Usability	Guidance based on monitoring
French et al., (2012)	Low back pain	Interactive workshop and DVD	✓	Patient-centered, Iterative, Theory driven	UK MRC, Theoretical Domains Framework	✓	Yes • Does not specify	Mentions behaviour change techniques		Mentions behaviour change techniques and models				✓		✓	Perceptions	Advice
Ng et al., (2014)	Insulin for Diabetes	Paper-based	✓	Patients and clinicians, Iterative	UKMRC & IPDAS, Ottawa Framework	✓	Expected Utilities, Prospect theories			Specifies modelling but no details		Content and presentation					Acceptability and feasibility	Pros and cons for treatment
Roberto et al., (2007)	Preventing Pregnancy, STD	Computer-based	✓	Theory-based			Theory of reasoned action, theory of planned behavior			Mentions about process model		Pre and post test control group design					Process evaluation and knowledge	Guidance
Akl et al., (2007)	Inhaled steroid	Computer-based	✓	Rule-based design	Ottawa Personal Decision Guide	✓	Ottawa Personal Decision Guide			Specifies model with probabilities		Navigation, structure, content					Expert and Patient	Rule-based guidance
Smith et al., (2009)	Screening	Booklet	✓	Rule-based design	IPDAS	✓	Probability-based			Patient stories							Acceptability and evaluation	Probability/ rule-based

Paper	Purpose	Format	Self-care	PtDA	Development	Framework	Needs	Theory	Application of theory to describe decision making	Natural Decision Making Process	Decision Process Modelling	Step-by-step decision process	Courses of Action	Interface	Integrate with other systems	Context	Organisation	Evaluation	DM Support
Lenert et al., (2014)	Share decision making	Computer-based	✓		Systems-based		✓	Rule-based system			Provides system architecture			Personalised user interface	Integrate with other systems	✓		Feasibility	Pros and cons for treatment
Gance-Cleveland et al., (2015)	Obesity intervention	Web-based	✓	✓	User-centered	CCM					Case-based Scenario					✓		✓	Guidance
Stroebel (2005)	Self-management	Phone, email, face-to-face	✓		Systems based	CCM					Algorithm							Usability Testing	Guidance
Tsiachnias et al., (2013)	Diabetes Self Care		✓		Systems based - patient, professional, organisation		✓	Multi-criteria							✓		✓	✓	Rule-based
Fonda et al., (2010)	Diabetes Self Care	Web and mobile-based	✓		User-centered design, system-based		✓				System workflow			✓		✓		Usability Testing	General guidance
Ko et al., (2014)	Cancer Screening	Multimedia		✓			✓		For DA					✓	✓			✓	Pros and cons for treatment
Yu et al., (2014)	Diabetes Self Care	Shared-decision making			User-centered, Iterative	Ontario, IPDAS	✓	Heuristics Evaluation - Human Factors										Usability Testing	General guidance



Paper	Purpose	Format	Self-care	PDA	Development	Framework	Needs	Theory	Application of theory to describe decision making process	Natural Decision Making Process	Decision Process Modelling	Step-by-step decision process	Courses of Action	Interface	Integrate	Context	Organisation	Evaluation	DM Support
Jangpatirun (2007)	Self-management	Dialectic	✓	✓	System-based							Flowchart						Usability	Pros and cons for treatment
Dowding et al., (2004)	Prostate and Hypertension treatment	Computer-based	✓	✓	Iterative design methodology		✓	Utility theory, Algorithm-based				Decision trees	✓					✓	Rule based
Dorfman et al., (2010)	Prostate cancer screening	Computer-based print based		✓	Redesign		✓											Usability and feasibility testing	Information based
Ahmed et al., (2011)	Asthma	Web-based	✓	✓	System-based	CCM	✓					Workflow		✓				✓	Action plan and symptoms tracking
Woo et al., (2014)	Chronic self-care	Web-based	✓		System-based							Rule-based		✓				✓	Rule-based guidance
Guo et al., (2015)	Diabetes Self Care	Mobile	✓		System-based		✓					user stories, Use case, user task descriptions						Pre and Post test	Diet management
Schoorelet al., (2014)	Delivery after Shared-decision making	Shared-decision making	✓	✓	Systematic development	IPDAS	✓					Predictive model		✓				Usability	Rule-based guidance
Hoffman et al., (2014)	Arthritis management	Web-based		✓	Theory-based, patient-centered	IPDAS, Human-Computer Interaction methods, Ottawa Framework	✓	Judgement heuristics and cognitive biases						Paper prototypes, Wireframes, Iterative process		✓		Iterative reviews	Pros and cons for treatment
Shogoh et al., (2013)	Epilepsy	e-tools, diary	✓	✓	user-centered, Iterative		✓	Behavioural theory and models						Iterative	✓			Usability	Risks evaluation

Step-by-Step Courses of Decision Making													
Application of theory to decision making													
Organisational Context													
Paper	Purpose	Format	Self-care	PDA	Development	Framework	Needs	Theory	Natural Decision Making	Process Modelling	Action	Interface	Evaluation
Hommons et al., (2013)	Chronic self-care	Mobile	✓		User-centered			Case-based reasoning	✓	Bayesian network		✓	Usability and reliability
Kelly-Blake et al., (2014)	Stress testing	Paper-based	✓		Cognitive interviews - systematic development process	IPDAS	✓		Mentions about theory			Content, language, appearance	Feedback - ease of use, evaluation of material
Simon et al., (2013)	Insulin for Diabetes	Web-based	✓		Systems-based	Algorithm		Decision algorithm		Flowchart, tasks and subtasks, schematic overview, scenarios			Usability and safety
Sunayev and Chorny (2012)	Chronic disease care	Mobile and e-diary	✓		Systems-based		✓			Use case, logical model, system components, logical data model		Integration with information and third party	Architecture, Usability, data quality
Almed (2011)	Diabetics self-management	Online	✓		Systems-based	Bayesian Framework	✓			Ontology Design, Flowchart, Framework		Graphical modeling interface	Iterative verification and testing
Or and Tao (2012)	Chronic disease care	based system paper	✓		Systems-based		✓	Heuristics		Cognitive Task design		Human factors design	Usability and end-user testing
Schmid et al., (2010)	Stroke prevention		✓		Intervention mapping		✓	✓		Strategies		✓	Options evaluation

Paper	Purpose	Self-care	Format	PDA	Development	Framework	Needs	Theory	Application of theory to describe decision making	Natural Decision Making Process	Decision Process Modelling	Step-by-step decision process	Courses of Action	Interface	Integrate	Context	Organization	Evaluation	DM Support
Jbaja-Weiss and Volk (2007)	Computerized Breast cancer treatment	✓	Computerized	✓	Software-based			Learning theory and entertainment	✓		Schematic diagram			Navigation, graphical user interface, audio, text, graphics, video					Options evaluation, probability
Aki et al., (2007)	Inhaled steroid therapy	✓	Computer-based	✓	Ottawa Decision Support Framework			Expected utility model.				Informed decision making model, paternalistic model, shared decision making model, physician as an agent model		Navigation, hyperlinks				Feedback and Pilot testing	"to use" or "not to use"
Pfäffli et al. (2012)	Cardiac rehabilitation exercise intervention	✓	Mobile and web		Iterative			Behavior change theories			Role-model							Pre-test and feedback	Self-care, treatment adherence
Zao et al., (2008)	Self-management	✓	Mobile		Activity-oriented design and Human-computer interactions.		✓	Activity theory			Systems design, tasks			Interaction styles - Screen layout and display, visual elements	Systems integration			Usefulness and usability evaluations	Self-care, treatment adherence
Fleisher et al., (2014)	Cancer clinical trials	✓	Web-based	✓	Systematic process map	Ottawa Decision Support Framework, IPDAS		Cognitive Social Health Information Processing Theory						Format, display and visual representation				User testing and feedback	Pros and cons of their treatment options



Paper	Purpose	Self-care	Format	PtDA	Development	Framework	Needs	Theory	Application of theory to describe decision making	Natural Decision Making Process	Decision Process Modelling	Step-by-step decision process	Courses of Action	Interface	Integrate	Context	Organi sation	Evaluation	DM Support
Ubink et al., (2008)	Asymptomatic abdominal aortic aneurysm			✓		IPDAS	✓				Algorithm based - risk scores			Simple, user-friendly				Usefulness and user-friendliness	Pros and cons of their treatment options
Carroll et al., (2013)	Cardioverter defibrillator treatment		Information and visual aids	✓		Ottawa Decision Support Framework and modified Delphi process		Theories from psychology, decision analysis, decisional conflict, and values, and self-efficacy.		Menions about natural process but no information				Information presentation				Acceptability, feasibility and decision quality	Pros and cons of their treatment options
Anchlal et al., (2013)	Hypertension	✓	Web-based	✓		Software based on algorithm	✓	Algorithm-based			Menions about system analysis - architectural			Design, Navigation and presentation	Integration of various systems, people	✓		Feedback on contents of the user interface and Rules and logic based	
Lenz et al., (2009)	Prevention of myocardial infarction for patients with type 2 diabetes		Video, booklet, worksheets	✓		Patient-centered MRC, IPDAS	✓	Menions about using theory			Component modelling			Presentation and layout				Pilot testing	Risks evaluation
Villalba et al., (2008)	Self-care system for heart failure patients	✓	Software		user-centered		✓		Scenarios, scheme		User modelling (persanas), scenarios modelling			Interaction design with work flows				Concept evaluation	Records analysed for complications
Kwon et al., (2005)	Oncology		Software	✓	Context-Knowledge-Dialogue-Data-Model	UBDSS					Systemic level view	Context-aware decision process				✓			Decision based on context

## REFERENCES

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